VNIVERSITAT DE VALÈNCIA

TESIS DOCTORAL

PhD. DISSERTATION

Enhancing the impact of interventions in chronic health: a transnational qualitative meta-study on sampling, recruiting and communicating with vulnerable populations

Programa de Doctorado en Diseño, Gestión y Evaluación de Políticas Públicas de Bienestar Social
Línea de investigación: Desigualdad, sociedades inclusivas y bienestar social e individual en el marco de las políticas públicas

Beatriz Vallina Acha

Dirección: Dr. Jorge Garcés Ferrer
Dra. Maria Teresa Ferrando García

En Valencia, Octubre de 2021

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A Eduardo y a Elías

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Aunque esta sección debiera ser en inglés, al igual que el resto de la tesis doctoral, no acababa de resultarme algo más allá de “sosa” y “protocolaria”, por lo que he decidido, al final, hacerla en español y añadir una versión traducida y abreviada justamente después.

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Abbreviations and acronyms

- AIDS - Acquired immunodeficiency syndrome
- CALD – Cultural and Linguistically Diverse (communities)
- CBPR – Community-based Participatory Research
- CDSMP – Chronic Diseases Self-Management Programme
- COPD – Chronic Obstructive Pulmonary Disease
- CSO/CSOs – Civil Society Organisation/s
- CVD - Cardiovascular disease
- EPP - Expert Patients Programme
- HCP / HCPs – Health professional/s
- HIC – High-Income Countries
- HIV – Human- immunodeficiency virus
- ICT – Information and Communication Technologies
- IT – Information Technologies
- LMIC – Low and Middle Income Countries
- MSc / MA – Master degree
- MSM – Men having sex with men
- PhD – Philosophy Doctor, doctoral degree
- QoL – Quality of Life
- SDoH - Social Determinants of Health
- Socio-Economic Status (SES)
- SOn - Specific Objective (number)
- SRn - Specific Research Question (number)
- STI – Sexually Transmitted Infections
- T1D - Type 1 Diabetes Mellitus
- T2D - Type 2 Diabetes Mellitus
- WSW – Women having sex with women

RESUMEN DE LA TESIS DOCTORAL (ESPAÑOL)

Contexto y problemática

La vulnerabilidad psicosocial de individuos y comunidades (y viceversa) está determinada por una compleja red de circunstancias que deben analizarse desde un enfoque interseccional y relacional. La mayor vulnerabilidad que afecta a determinados grupos sociales actúa también en detrimento de su educación en salud, el acceso a la atención médico-sanitaria y la comunicación con profesionales de la salud, lo que repercute en su proceso de toma de decisiones y en su autogestión de la salud.

Las consecuencias de las desigualdades en salud son múltiples y complejas: esta tesis doctoral se centró en cómo estas consecuencias impactan la comunicación y la educación en salud; también analiza la experiencia vívida de la enfermedad crónica y las cuestiones sociales de la salud comunitaria.

* * *

Los Determinantes Sociales de la Salud (DSS) pueden estar implicados incluso en factores constitucionales: por ejemplo, ciertos elementos del exposoma estarán presentes en la constitución a largo plazo, a nivel psicobiológico, de cada individuo. Los recursos, las relaciones, las comunidades, las organizaciones y los co-determinantes estructurales de las disparidades de salud que puedan observarse a nivel individual necesitan ser analizados a nivel estructural, si es que aspiramos a comprender el panorama completo que presenta la compleja red de co-determinantes. Las desigualdades en salud son situaciones "injustas y evitables" de privilegio y opresión, causadas y reproducidas por las políticas públicas y por las opciones de estilo de vida profundamente influenciadas por factores estructurales." (Dahlgren and Whitehead 2007, 1).

Las situaciones de mayor vulnerabilidad psicosocial y de desventaja en el campo social afectan e impactan la comunicación paciente-profesional de la salud, la capacidad de acceder a educación para la salud y a información sobre la salud, y, por tanto, a la autonomía de los pacientes. Estas situaciones socavan las habilidades y la eficacia de los pacientes en la toma de decisiones y su capacidad de gestión y autocuidado en situación de cronicidad (Edwards, Davies y Edwards 2009). Todo ello también se ve reforzado por el **modelo médico tradicional,** que supone una importante barrera a través de una potencial reticencia a la promoción de un papel proactivo, participativo y autónomo en las y los pacientes (Joseph-Williams, Elwyn, y Edwards 2014). Debido a su situación social, económica, cultural y ambiental, algunas personas y comunidades en situación de mayor vulnerabilidad podrían ser, también, reacias a ser contactadas por el personal de servicios sociales y por el sistema de salud; dichos grupos, a veces, podrían considerarse de difícil acceso o *hard-to-reach* (Duvnjak y Fraser 2013; Shaghaghi y Aziz Sheikh 2011). Esta ruptura entre los individuos, las comunidades y el sistema de salud contribuye a la reproducción de la desigualdad y aumenta las situaciones y gravedad de la marginación y exclusión social.

* * *

Salud, ingresos y educación interactúan de una manera compleja; específicamente, la clase social es un co-determinante importante de la salud , que comprende las posiciones socioculturales y socioeconómicas, influenciadas por la educación y las credenciales, los ingresos, la autonomía o la independencia en el lugar de trabajo, entre otros factores (E. O. Wright 1983; 1992). La salud y la educación son dos dimensiones muy relevantes para el crecimiento social y económico: la influencia mutua de la educación y la educación viene siendo estudiado desde la década de 1960 (Schultz 1961; Becker 1975); en concreto, el número de años de educación de las personas parece estar vinculado a su esperanza de salud y longevidad (Fuchs 1979). Mientras que los avances en medicina, farmacología y biotecnología también deben tenerse en cuenta, es necesario reconocer el rol del sistema productivo y sus cambios a lo largo del tiempo, así como el papel de la planificación social de la salud.

La salud, las desigualdades de ingresos y la mortalidad han mostrado una relación más compleja si cabe. La investigación demuestra cierto efecto de la desigualdad de ingresos en la mortalidad, pero que desapareció controlando la variable educación – es decir,una vez que los sujetos terminan la Educación Secundaria (Muller 2002). Una explicación multicausal considerando la salud, la nutrición y la educación explica cómo los efectos de prolongar los años de escolaridad podrían reducir los resultados adversos para la salud (Tillmann et al. 2017). Existe una correlación significativa entre las enfermedades crónicas y las categorías profesionales poco cualificadas, que suele asociarse a los ingresos (M. O'Mahony y Samek 2016). La salud, la educación y el capital humano de los individuos tienen, por sí mismos, un papel importante en la Salud Pública. Por ejemplo, un ciclo indeterminado de pobreza o crisis financiera puede suponer desnutrición de niños y adultos –incluidas las mujeres embarazadas– lo que, a medio y largo plazo, podría reducir su productividad de la fuerza laboral y, por tanto, la movilidad social (Frankenberg y Thomas 2017). Además, los ingresos, los años de educación (formal) y el acceso a la educación continua (no-formal, educación a lo largo de la vida y en el puesto de trabajo) afectan las competencias de las y los individuos para acceder, seleccionar y utilizar información, evaluarla como confiable y adquirir nuevos conocimientos a partir de ella; específicamente, puede afectar la capacidad individual para adquirir una apropiada educación en salud y poder mejorar su autogestión de la enfermedad, su calidad de vida, su rol en la toma de decisiones y su rol activo y proactivo para modelar el pronóstico y el curso de la patología. La heredabilidad (Bourdieu y Passeron 2008) también debe tenerse en cuenta al analizar las opciones presumiblemente individuales, arraigadas en su propia cultura o subcultura, y reproducidas generaciones tras generación. Considerando también los co-determinantes medioambientales, hemos de tener presentes las teorías más recientes sobre el exposoma, como co-determinante social, ambiental y constitucional de la salud (O. Robinson et al. 2018; O. Robinson y Vrijheid 2015; Vrijheid et al. 2014).

Esta tesis doctoral también consideró otras situaciones subyacentes al ámbito social y las circunstancias estructurales relacionadas con las desigualdades en salud: véase el trabajo informal, el cuidado informal y el trabajo reproductivo, las intersecciones entre género, etnia, cultura o edad, entre otros, y otras realidades cambiantes con importante impacto en la salud.

* * *

La presente tesis considera, de principio a fin, el hecho de **las diferencias de poder**, tanto dentro del sistema sanitario como en el campo social (pe., entre profesional de la salud y paciente). Las diferencias de poder a nivel micro-social impactan en el acceso (y la falta de éste) al sistema de salud, la información y la toma de decisiones. Las diferencias de poder y las posiciones ocupadas por cada sujeto dentro del campo social, la descripción del mecanismo capaz de impactar en su vida y en sus opciones-decisiones, y los comportamientos y actitudes de todos los actores – incluyendo intereses, objetivos y metas, influencias y decisiones potenciales en salud y cuidado – se consideran conjuntamente con la *reproducción cultural* y la transmisión de normas y valores.

Una atención adecuadamente diseñada y bien adaptada a la atención clínica y social de la cronicidad, específicamente considerando el riesgo de exclusión y las situaciones de marginalización, la situación de discriminación real y socio-histórica, tiene el potencial de mejorar la salud de dichas comunidades y, por lo tanto, la salud pública (Dahlgren y Whitehead 2007),contribuyendo así a la sostenibilidad de los sistemas de salud pública, el estado de bienestar y la inclusión e igualdad de toda la ciudadanía. El progreso hacia la igualdad requiere una reforma profunda, estructural y cultural, así como la formulación de políticas sanitarias inclusivas, y necesita del el empoderamiento de estas comunidades pues a pesar de que las personas en situación de mayor vulnerabilidad y/o privación a menudo tienen peores resultados de salud, el problema está profundamente arraigado en las condiciones estructurales y enmarcado dentro de un complejo sistema de co-determinantes sociales, económicos, culturales y ambientales. **Las condiciones estructurales** afectan las decisiones y vivencias, hábitos, comportamientos, opciones verdaderamente disponibles y al acceso a la salud y educación. Todos estos factores individuales están co-determinados por varias circunstancias sistémicas, subyacentes a la mera apariencia individual, estando la gran mayoría fuera del control de cada sujeto. **Ha sido, consecuentemente, necesario abordar esta área problemática desde una perspectiva interseccional, crítica y relacional**, considerando la clase social, la etnia y la/s cultura/s, el sistema sexo/género, las circunstancias materiales y naturales, la educación, las comorbilidades, los factores constitucionales.

Preguntas de investigación y objetivos

Dadas las múltiples dimensiones y la complejidad de la temática, o temáticas, entrelazadas en esta investigación, el punto de partida implicó el definir un conjunto de preguntas de investigación flexibles pero lo suficientemente explícitas y aplicables en la práctica investigadora. La siguiente tabla refleja la relación entre las preguntas de investigación, los temas a tratar y las fases de investigación:

Tabla 1 – Relación entre las preguntas de investigación y las temáticas a abordar con las etapas de la investigación

Pregunta de Investigación (RQ)	Temática
RQ1 - ¿Cuáles son las principales barreras y facilitadores para la comunicación en salud y, específicamente, para la obtención de información, el reclutamiento de poblaciones de difícil acceso y la facilitación del acceso a iniciativas de educación informal sobre alfabetización en salud con vistas a dar apoyo al empoderamiento colectivo e individual?	Núcleo de la investigación: comunicación en salud y compromiso de pacientes en poblaciones de difícil acceso con enfermedades crónicas • Intervenciones culturalmente competentes: muestreo y reclutamiento.

	• Necesidades y uso de la información obtenida; falta de gestión de la información. • Comunicación con los profesionales de la salud: roles, cuidado y autocuidado en la consulta médica • Comunicación y coproducción de investigaciones • Apoyo entre pares y educación entre pares; relaciones interpersonales en programas basados en pares y grupos de apoyo mutuo. • Información y difusión de la salud crónica en Internet; Uso de las TIC y comunidades virtuales
Etapas de la investigación	• Síntesis cualitativa dentro del Análisis (todas las secciones) • Análisis iterativo y comparativo y revisión de la literatura reflexionado sobre el marco conceptual y la discusión.
Específico-RQ2. ¿Cómo estas barreras afectan el autocontrol de las enfermedades crónicas? Específico-RQ3. ¿Cómo impactan estas barreras en la obtención de información de salud? Específico-RQ4. ¿Cómo afectan estas barreras al pronóstico? Específico-RQ4.1. Por el contrario, ¿cuáles son los facilitadores que mejoran la auto-gestión de las enfermedades crónicas y la adquisición de información de salud y cómo estos impactan en los resultados de salud y pronóstico a nivel individual?	• Dimensiones de la comunicación en salud: comunicación intrapersonal e interpersonal. Neutralidad valorativa y conflicto de intereses en la difusión de información científica: práctica socialmente informada de comunicación. Desafíos éticos. Eficacia y aceptabilidad de la comunicación; • Empoderamiento y autogestión de la salud.
Etapas de la investigación	• Síntesis cualitativa dentro del AnálisisAnálisis comparativo y revisión de la literatura dentro del marco conceptual y la discusión
Trasversales	Análisis multidimensional del concepto de "vulnerabilidad social": intersecciones sistémicas y determinantes sociales de la salud (DSS).
Etapas de la investigación	• Marco teórico • Discusión • Revisión y síntesis de la literatura dentro de la base teórica y la discusión

Alineado con la investigación y el planteamiento del problema, el objetivo general era el estudio de las posibles vías y alternativas en entornos clínicos - y, en un sentido más amplio, dentro de la interacción social - que permitieran revelar y gestionar el impacto de la discriminación y vulnerabilidad en la salud y en la patología crónica de personas y comunidades, pero también las consecuencias, barreras y facilitadores para su empoderamiento y participación activa en la intervención, innovación e investigación sanitaria y sociosanitaria.

Los objetivos específicos fueron 3. En primer lugar, determinar cómo la comunicación entre pacientes y profesionales de la salud podía afectar el compromiso, la participación y la retención en la atención médica, específicamente para pacientes vulnerables con condiciones crónicas altamente prevalentes; se prestó especial atención a los efectos de esta comunicación en la participación de los pacientes en la educación sanitaria informal y en las habilidades de autogestión y autocuidado de los pacientes.

Directamente relacionado con el objetivo específico anterior, el **segundo objetivo era desvelar el impacto de la toma de decisiones conjunta en la proactivividad de los pacientes en la toma de decisiones y cómo dicha proactivividad influye en la adquisición de hábitos más saludables y rutinas de autogestión**. Secundariamente, también se pretendía analizar el impacto de la toma de decisiones conjunta en la mejora de los resultados de salud.

El tercer objetivo específico consistió en **analizar las barreras y los facilitadores que se encuentran las y los pacientes para acceder a la información sanitaria en varios contextos**: asesoramiento clínico y consulta médica, medios de comunicación online y medios tradicionales, campañas de comunicación de salud pública (ambas realizadas por entidades públicas o privadas, como administraciones u ONG, respectivamente), difusión y comunicación de la ciencia y de la investigación, y todas las acciones destinadas a difundir ampliamente los resultados de la investigación en la sociedad general, así como programas de educación y alfabetización sanitaria, incluidos también grupos de apoyo mutuo, o entornos basados en la iniciativa comunitaria.

Dado el enfoque iterativo y amplio de la presente tesis doctoral, el objetivo específico fue analizado, discutido y traducido en recomendaciones para la práctica y a lo largo de toda la tesis.

El último objetivo específico fue **operacionalizar el concepto de "vulnerabilidad social"**. Tanto el marco teórico y el marco conceptual, desarrollados iterativamente durante toda la duración de la presente investigación, reflejan los resultados de este objetivo proponiendo una perspectiva interseccional y socioecológica capaz de analizar, utilizar, sintetizar y llevar a la práctica de forma crítica el amplio y vago concepto de "vulnerabilidad social".

Metodología

El tipo de metaestudio fue una síntesis cualitativa en conjunción con los principios de la teoría fundamentada; este enfoque innovador se ha decidido para garantizar el (i) rigor y exhaustividad del análisis de los resultados, así como las conclusiones, modelos construidos y las implicaciones para la práctica; y (ii) la efectividad y agilidad de la teoría fundamentada al ser aplicado a una muestra muy considerable de estudios (n=103). Por un lado, la metasíntesis es capaz de abordar una amplia gama de estudios, incluyendo intervenciones en contextos de alta complejidad socio-cultural e incluso metodológica; permite la construcción de nuevos conceptos, marcos interpretativos y teorías, suponiendo en sí misma un enfoque innovador y contribuciones al campo inéditas, tal como es requerido, por definición, en una tesis doctoral. Esta tesis doctoral tiene como hilos conductores, principalmente, la comunicación de la salud, en un sentido amplio, y la educación en salud y, sobre todo, en cronicidad y enfermedades crónicas de alta prevalencia dentro de comunidades marginalizadas, excluidas o consideradas vulnerables tomando como referencia un punto de partida interseccional. El hecho de haber optado por un enfoque de investigación cualitativa nos permite analizar los principales temas y cuestiones relacionados con esta temática, teniendo en cuenta las metáforas, costumbres y uso de todos los participantes "en sus propias palabras". Por otro lado, la aplicación de la teoría fundamentada permite organizar grandes unidades de texto de forma estructurada, a la vez que ágil y rigurosa, permitiendo que del texto íntegro de cada uno de los estudios puedan emerger temáticas y conceptos intertraducibles que nos permitan re-elaborar modelos construir teoría.

Este metaestudio solo incluyó artículos publicados en revistas académicas con revisión de pares y tesis tanto doctorales como de máster (Trabajos Fin de Máster o MSc. Dissertations, en inglés) con motivo de asegurar que partíamos de trabajos de calidad y relevancia adecuada, tanto en riqueza conceptual como en muestra. Los estudios incluidos son (1) primarios y (2) cualitativos. Su calidad se evaluó, igualmente, a posteriori, a través del Critical Appraisal Skills Programme o CASP ampliamente utilizado en la investigación meta-etnográfica. Previamente al primer filtro y selección de estudios, se eliminaron duplicados y artículos no directamente relacionados para asegurar la relevancia de la síntesis.

Etapas de la investigación

Definición del tema de investigación. A través de una revisión narrativa e interpretativa de la literatura de una perspectiva sociológica y filosófica, que duró aproximadamente 6 meses, se formularon las primeras preguntas de investigación.

Definición de la estrategia de búsqueda. La búsqueda bibliográfica se realizó en la base de datos de la Universitat de València (Trobes) y Google Scholar. Trobes incluye Cochrane Library, SCOPUS, Web of Science, Journal Citation Reports, MedLine, Proquest Central o Proquest, entre otras, especificadas en http://trobes.uv.es/search*spi/. Google Scholar se utilizó para encontrar literatura gris revisada por pares, evitando el sesgo de publicación. En ambas bases de datos se utilizaron las siguientes palabras clave:

- Qualitative study
- Health communication
- Recruitment
- Empowerment
- Engagement
- Chronic
- Long-term condition
- Participation
- Vulnerable
- Recruitment
- Hard-to-reach

Se llevaron a cabo dos búsquedas: la primera, con *((qualitative study) OR (experience)) AND ((health communication) OR (health dissemination)) AND (recruitment) AND (empowerment) AND ((chronic) OR (long-term condition))* ; la segunda de ellas, con los criterios de exclusion, ie.,: *(health communication) AND ((recruitment) OR (engagement) OR (participation)) AND ((vulnerable) OR (hard-to-reach)) AND (qualitative) AND (chronic diseases) AND (systematic review) NOT (meta-synthesis) NOT (meta-analysis) NOT (elderly) NOT (children) NOT (developing countries).*

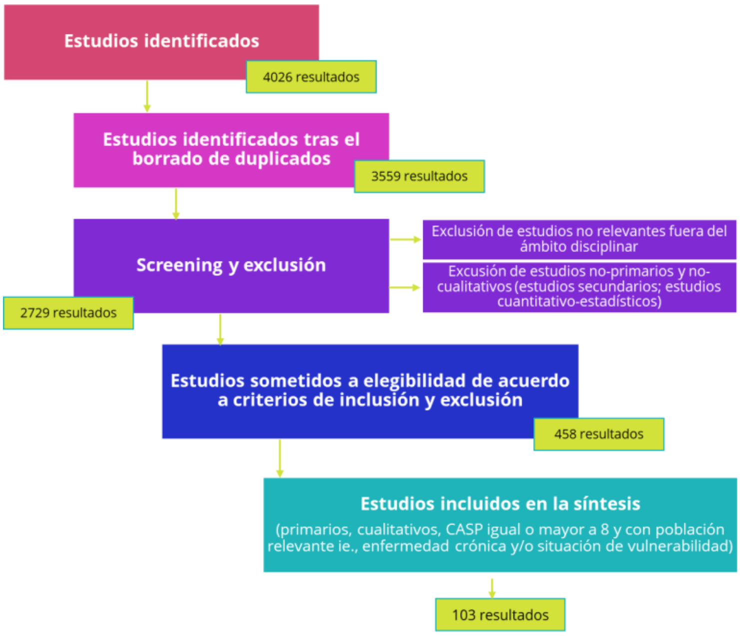

Ilustración 1 - Estrategia y resultados de la búsqueda

Eliminación de duplicados. Las bases de datos bibliográficas a menudo ofrecen una amplia gama de resultados duplicados; después de exportar a Zotero todas las referencias resultantes de las dos búsquedas bibliográficas (primaria y secundaria), se eliminaron los duplicados.

Definición de los criterios de admisibilidad. Los resultados iniciales mostraron 4026 referencias (3559 después de eliminar duplicados; 2729 después de eliminar resultados irrelevantes y no relacionados) de 2008 a 2018, que comprenden la crisis del ejercicio económico y financiero. Dado que las crisis financieras implican recursos limitados dedicados a la promoción de la salud, investigar cómo fomentar la comunicación, la alfabetización, la autogestión, el empoderamiento y la coproducción en un período de crisis tenía un claro interés intrínseco.

Tabla 1 - Criterios de inclusión y exclusión

Inclusión	Exclusión
Revisado por pares (artículos, disertaciones de doctorado…) Estudio primario Estudio cualitativo Estudio de métodos mixtos De 2008 a 2018 (crisis económica y recuperación parcial) Países de ingresos altos (transferibilidad de los resultados) Poblaciones adultas (18 – 65 años de edad) En situaciones de vulnerabilidad psicosocial CASP≥8	Conflicto de intereses declarado. Muestra no clara de participantes.

Luego, se importaron 2729 resúmenes a Zotero y, posteriormente, a MAXQDA, para ser examinados atendiendo al tipo de estudio y la relevancia de los trabajos.

Lectura de resúmenes y decisión sobre criterios de relevancia: Una vez importados a MAXQDA, se analizaron todos los títulos y resúmenes y se seleccionaron los más relevantes. Se formaron dos grupos: los artículos incluidos en la primera selección, y los artículos potencialmente relacionados que podrían ayudar al marco teórico, documentos de construcción de teoría y a considerar en el marco conceptual y teórico, así como en la problematización (revisiones sistemáticas, meta-análisis, meta-síntesis o artículos de investigación estadística, cuantitativa o de metodologías no consideradas en los criterios de inclusión pero con gran relevancia conceptual).

Tipos de artículos: se incluyeron estudios de primarios cualitativos (siendo admisibles los métodos mixtos), sin conflicto de intereses, con supuestos teóricos y perspectivas claramente establecidos, con una población de estudio apropiada.

- **Publicaciones**. Trabajos publicados en revistas académicas o de investigación (trobes+), actas de congresos (google scholar), tesis doctorales y trabajos fin de máster (en la denominación correspodiente a cada país) y documentos de trabajo (research gate) de 2008 a 2018 (de inicio a fin del periodo de crisis financiera y social.
- **Participantes**: Personas adultas (mayores de 18 años y menores de 65, sin prejuicio de que en grupos de discusión puedan existir personas mayores

de 65 años siempre y cuando haya personas adultas en diferentes rangos de edad, no sea definitorio y responda a la lógica de la investigación) con enfermedades crónicas, vulnerables y/o en riesgo de exclusión social; Médicos, profesionales y profesionales de la salud. Investigadores en el campo de la salud pública o la epidemiología social realizando estudios a través de métodos participativos basados en la comunidad (CBRP o Community-based Participatory Research. Restricción geográfica: países desarrollados o HIC (High-Income Countries) y sistemas suficientemente similares al contexto europeo actual

- **Tipo de datos:** datos cualitativos obtenidos directamente de los participantes. Comentarios de las autoras o autores de los estudios.

Resultados relevantes: Fueron relevantes las opiniones y creencias de los participantes sobre la salud y el cambio de comportamiento aplicado a los comportamientos relacionados con la salud. Impresiones y experiencias sobre la comunicación entre médicas-os/especialistas/enfermeras/profesionales de la salud (general;otros) y pacientes (bidireccionalmente). Experiencias en comunidades offline u online de pacientes. Experiencias en educación para la salud no formal e informal (impartido por profesionales de la salud, pares o cualquier otra figura relevante para la investigación, como mediadoras-es comunitarias-os). Opiniones, experiencias y lecciones aprendidas por los investigadores que intentan realizar un estudio basado en metodologías participativas basadas en la comunidad o CBPR. Comentarios de los propios autores y autoras de los estudios.

458 estudios fueron escaneados y evaluados para la selección final, considerando los criterios de inclusión y el control de calidad a través del cuestionario del CASP para trabajos de investigación cualitativa. Se creó una base de datos con los ítems CASP, la puntuación total de cada artículo y los criterios de inclusión y exclusión.

Construcción de conceptos: Se analizaron todos los resúmenes de la selección preliminar (458 artículos y tesis doctorales): los datos cualitativos se explotarán utilizando un conjunto de conceptos para dejar emerger el primer enfoque conceptual y definir las cuestiones de selección definitivas relacionadas con la relevancia. Las preguntas de selección son Año, Lugar, Enfermedad, Tema, Muestra, Tipo de participantes, Tipo de estudio, Conflicto de intereses declarado e inclusión de extractos/citas (transcripción literal)

Criterios de relevancia: Se aplicaron criterios CASP a todos los artículos y tesis doctorales para evaluar la calidad; se evaluó la relevancia de los artículos y disertaciones de acuerdo las preguntas de selección formuladas anteriormente.

Finalmente, se conservaron 103 estudios que cumplían todos los criterios de inclusión y fueron calificados como excelentes (CASP≥8) en la muestra final.

Análisis-Síntesis-Análisis: Una vez seleccionadas las contribuciones de alta calidad se inicia un proceso iterativo para analizar y sintetizar la investigación cualitativa. Los conceptos identificados durante el proceso de evaluación fueron los datos brutos para las primeras etapas de síntesis. La distinción entre conceptos y temas es difusa, pero definimos los conceptos como aquellos que tienen cierto poder analítico o conceptual, a diferencia de los temas, más descriptivos.

Organización de los hallazgos en grupos: Posteriormente, la síntesis continuó auto-reflexivamente intentando esclarecer cómo se relacionan los estudios y los resultados entre sí

Traducir estudios entre sí (dentro de grupos) o *traducciones recíprocas*: Se prosiguió analizando si los estudios tienen conceptos/metáforas diferentes ante las mismas "etiquetas" conceptuales o temáticas, o si refieren a la misma idea.Se hicieron sendos resúmenes de los conceptos de cada grupo para trazar las relaciones entre ellos así como los modelos, proporcionando un mapa útil de la síntesis

Sintetizando traducciones a través de grupos y creando una teoría de rango medio. Ello requirió comparar las traducciones textuales de cada grupo leyendo y releyendo cada una de las traducciones recíprocas y analizando temáticamente los datos que se averigüen para reconceptualizar los hallazgos.

Por último, los pasos 8 a 11 surgieron en cuatro dimensiones:

1. Comunicación en contexto clínico
2. Programas de educación para la salud
3. Adherencia, autogestión de la salud y toma de decisiones
4. Empoderamiento de los individuos y las comunidades

Dentro de cada categoría, se diferenciaron los facilitadores y las barreras, así como los temas emergentes; para el análisis, se utilizó el modelo socioecológico para desvelar los determinantes y factores clave que influyen en cada dimensión a nivel micro, meso y macro.

También surgió una quinta categoría: reclutamiento e involucramiento de personas vulnerables para proyectos de investigación y ensayos utilizando métodos comunitarios y de coproducción: los resultados completos de la quinta categoría se publicarán por separado.

Conclusiones

Esta tesis doctoral abordó la cuestión sobre la comunicación en la consulta clínica con poblaciones en situación de vulnerabilidad, el papel y las posibilidades de la alfabetización sanitaria y el acceso a la información, la autogestión de la salud los factores integrados en el proceso de toma de decisiones, la relación entre la autonomía de los pacientes, el empoderamiento comunitario y los cambios sociales y políticos; de forma transversal, esta tesis también analizó someramente los retos que las tecnologías y la eSalud suponen para las poblaciones desfavorecidas y altamente vulnerables.

Los mecanismos estructurales subyacen a las dificultades y disparidades de los pacientes y las comunidades en la comunicación sanitaria y, también, al acceso a la información y la educación sobre salud, repercutiendo en la toma de decisiones, la autogestión y los resultados sanitarios.

Todos estos aspectos fueron analizados enmarcados dentro del **modelo socioecológico** e integrando dentro del análisis un enfoque interseccional capaz de considerar diferentes co-determinantes de la salud, la comunicación en salud y el acceso a la atención de salud y la alfabetización en salud. Cada factor y co-determinantes interactúan entre sí y están interrelacionados con las condiciones estructurales y las circunstancias materiales a nivel social.

La educación, el género y el sexo, la raza, el origen étnico y la cultura, la privación material, la edad, la funcionalidad física o cognitiva y las políticas públicas fueron los factores más importantes revelados durante la investigación: su influencia e impacto están arraigados a nivel macro, estructural (incluyendo también la función física y cognitiva dentro del análisis estructural, impactado por el capacitismo y el mentalismo dentro del sistema de salud y, en general, del campo social). Sin embargo, también surgieron los co-determinantes a nivel individual-intrapersonal: la autoeficacia, la motivación y la personalidad han mostrado un impacto esencial en la comunicación, la alfabetización en salud, la participación en programas de educación para la salud, la autogestión o la toma de decisiones; sin embargo, debe reconocerse de forma explícita cómo estos factores individuales/psicosociales a nivel micro están profundamente influenciados por los entornos de las comunidades y también por las condiciones estructurales o sistémicas.

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La comunicación en la consulta clínica depende del intercambio de información pero, lo que es más importante, del desarrollo relacional. La información es un factor crítico para fomentar la autonomía de los pacientes y promover su capacidad, habilidades y competencias en la toma de decisiones. La información también apoya el proceso de creación de confianza y la relación terapéutica, bien al proporcionar suficiente información, de acuerdo con las demandas informativas de los pacientes, bien al prestar atención y "ajuste" mediante el estilo de comunicación y las habilidades sociales de ambas partes. La confianza, la autonomía y la proactivividad y disposición al autocuidado son factores críticos en la divulgación o no de información clave hacia y por parte de las y los pacientes.

Los desequilibrios de poder se consideraron dentro de la investigación desde sus propios fundamentos teóricos y analíticos; en este contexto, el "poder" refleja las capacidades de los pacientes para participar en el asesoramiento y tomar decisiones sobre su propio itinerario de autogestión y su tratamiento; a la inversa, los desequilibrios de poder en la relación entre proveedores y pacientes pueden reflejarse en "contratos encubiertos", presuposiciones y expectativas de ambas partes: la autoridad médica, el poder y las credenciales / conocimientos se entrelazan de forma compleja en la consulta médica. Si bien el término "empoderamiento" se ha intentado evitar, en general, en entornos individuales, el poder de los pacientes puede referirse a la autoeficacia y al sentido de autonomía: ambas dimensiones también se integran durante todo el análisis.

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Con respecto **educación previa,** la presente tesis ha considerado su potencial para obtener la alfabetización en salud. Una buena educación en salud, autoeficacia y el acceso a la información son los facilitadores más significativos para la educación informal (educación para la salud autodirigida); también el entorno social inmediato (compañeros, amigos, familiares o compañeros de trabajo), asociaciones de pacientes, comunidades y actores comunitarios, expertos y profesionales de la salud desempeñan un papel importante. Las desigualdades socioculturales y las disparidades económicas suponen una barrera crítica para la educación informal en salud, lo cual es muy problemático: la alfabetización en salud está relacionada con el conocimiento sobre medicamentos, el autocuidado y el autocontrol de enfermedades crónicas. Por lo tanto, la falta de alfabetización sanitaria puede tener un impacto negativo en la adquisición de comportamientos de salud. Además, la alfabetización en salud es un factor crucial en la toma de decisiones: el sentido de autonomía y control que los pacientes obtienen a través de la toma de decisiones y la reafirmación del yo es un poderoso motivador para el cambio, para la adopción de rutinas más saludables y para aumentar, aún más, su autoeducación y autocuidado.

La implementación de programas de educación para la salud con personas en situaciones de mayor vulnerabilidad también presenta desafíos, siendo los más importantes la involucración en el programa y la retención de participantes. El compromiso con el estudio en términos de retención está mediado por la clase social y, por lo tanto, las circunstancias económicas, la carga de trabajo, las posibilidades y la flexibilidad del horario de trabajo, las credenciales, la educación previa y la capacitación en el trabajo, pero también por las prioridades y objetivos de cada participante y sus comunidades y culturas o subculturas, la personalidad y otros factores psicológicos y la salud física. La investigación revisada mostró que la coproducción tiene el potencial de fomentar la sostenibilidad de los grupos y proporcionar un entorno seguro, respondiendo a las necesidades de los participantes y reuniendo a personas similares capaces de construir relaciones y alianzas a largo plazo, generando también un sentido de identidad y comunidad, y respondiendo a la necesidad de intercambiar experiencias y conocimientos en un entorno seguro y confiable. El compromiso, entonces, parece vinculado, en línea con la literatura, al empoderamiento de las comunidades: no se debe ignorar el potencial de los programas de educación para la salud y los grupos de apoyo mutuo para crear y mantener alianzas y estructuras cohesivas capaces de impactar en la promoción de la salud, ie., en la salud comunitaria.

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La **información bien adaptada** se ha revelado como un poderoso motivador para el cambio y para adquirir comportamientos más saludables. Teniendo en cuenta lo previamente indicado sobre la autogestión de la salud, si bien los factores psicológicos y de los individuos juegan un papel importante, también intervienen factores socioculturales y socioeconómicos. Las dificultades financieras, las dificultades económicas y, de nuevo, los desafíos relacionados con el lugar de trabajo y las obligaciones en el trabajo informal y reproductivo (por ejemplo, el cuidado informal) son barreras para la autogestión de cualquier condición crónica, aunque también mediada por factores individuales: la autorreflexión, la autoeficacia, la proactividad, las habilidades para establecer metas o las habilidades de planificación son transcendentales, así como el apoyo social y familiar y el entorno.

La educación en salud y la auto-gestión de la enfermedad crónica influyen en la toma de decisiones, en términos de disposición y actitudes por parte del paciente; la autoeficacia, una vez más, aparece conjuntamente con la proactivividad como co-determinante en la toma de un papel activo en la atención sanitaria. La naturaleza de la consulta clínica, el clima colaborativo y la relación terapéutica también aparecieron destacados como facilitadores. La edad, el género y la exclusión social son factores limitantes importantes que pueden afectar la disposición de los pacientes a una toma de decisiones proactiva y participativa.

En términos de autocuidado y toma de decisiones, una perspectiva individualista que ignore los factores estructurales, culturales y comunitarios no ofrecerá una imagen confiable y rigurosa. El ignorar las condiciones sistémicas que interfieren en el comportamiento de los individuos puede llevar a la reproducción de las desigualdades y la exclusión. La humanización y la atención centrada en la persona deben integrar una comprensión multidisciplinaria, crítica e integral de las diferencias de poder en los entornos clínicos y el campo social, y de los determinantes sociales, culturales, económicos, ambientales y estructurales subyacentes a esas disparidades.

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El empoderamiento colectivo requiere individuos autónomos; los individuos autónomos deben actuar dentro de un contexto de empoderamiento colectivo: los individuos y las comunidades interactúan permanente y continuamente. Los individuos no están aislados de sus realidades históricas, culturales y sociales; las comunidades están compuestas por individuos heterogéneos y construidas a través de su reflexión y autorreflexión histórica, cultural y social.

Individualmente, la autonomía y las posibilidades reales o potencial de autonomía están determinados cultural y socialmente. La expresión del *control* de los pacientes y el reflejo de la *autonomía* de los pacientes implican la independencia, la interdependencia (por ejemplo, las comunidades, el sistema/personal sanitario), la información disponible y accesible, las competencias para acceder a esa información, sus habilidades y autoeficacia para tomar decisiones cruciales en los ámbitos de la salud y el autocuidado y los factores ambientales y sociales, incluidos los estructurales (políticas, infraestructuras, tipo de sistema sanitario, crisis económica o repuntes, etc.)

Colectivamente, las comunidades pueden encontrarse con verdaderos desafíos y barreras para cumplir con las recomendaciones de salud pública: falta de recursos, problemas para acceder a los servicios de salud o sociales, seguros o tarifas, infraestructuras deficientes y problemáticas socio-económicas (vivienda, inseguridad alimentaria o inseguridad laboral). No es una circunstancia remota y rara: el conflicto entre dos realidades muy distintas (los promotores de las campañas de comunicación en salud y las comunidades marginadas) genera un choque entre las pautas y propuestas de estilo de vida y el potencial, las posibilidades y las circunstancias reales de las comunidades que puede resultar en un proceso alienante; en última instancia, en confusión, incomprensión, frustración y desconfianza. **La coproducción** de directrices e innovaciones en materia de atención médica, intervenciones basadas en la comunidad y procesos participativos, creación de confianza y enfoques ascendentes resultan cruciales.

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Una vez más, y en línea con el punto anterior, la coproducción y co-creación de herramientas e innovaciones tecnológicas es una necesidad crítica si los beneficiarios son individuos o grupos en situación de especial vulnerabilidad: el contexto comunitario, las condiciones culturales, económicas y ambientales, el acceso a las tecnologías y la brecha tecnológica, la falta de infraestructuras que podrían suponer también una falta de conectividad, sus prioridades y necesidades más urgentes, así como sus posibles reticencias y voluntad, deben evaluarse cuidadosamente para dar prioridad a las intervenciones con potencial de ejecución, aceptación y adopción.

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Los resultados mostraron claramente una relación entre el acceso a la información y (i) la comunicación paciente-profesional de la salud; ii) alfabetización sanitaria (la capacidad de autodirección de la educación en salud no estructurada o informal, la disponibilidad y preparación para participar en programas de educación sanitaria y la capacidad de aplicar los conocimientos adquiridos en entornos reales); y iii) la toma de decisiones. El acceso a la información y las competencias para seleccionar, evaluar y aplicar o utilizar la adquirida se relaciona con la proactividad, la capacidad de adoptar un papel activo en la toma de decisiones y, colateralmente, la autonomía de los pacientes. Aparte de la discriminación y/o el estigma, los co-determinantes más importantes de la salud de las comunidades son la clase social de los individuos, la educación previa y su propio entorno social inmediato. A nivel colectivo, el empoderamiento de estas comunidades requiere acceso al conocimiento, medios significativos y contextualmente relevantes, pero también identidad y vínculos, (re)apropiación y dignificación de sus idiosincrasias.

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Estos procesos de empoderamiento requieren un cambio de paradigma y una comprensión profunda de las desigualdades sociales y estructurales: la práctica clínica es un paso crítico en la promoción de la autonomía y el papel activo de los pacientes, su alfabetización en salud y el acceso de las comunidades más vulnerables a la información, el conocimiento y los recursos. Esta tesis doctoral propuso la denominada Práctica Clínica Crítica, que implica una comprensión completa e integral de las diferencias de poder entre individuos y grupos, la conciencia de cómo estos se reflejan en el asesoramiento y las relaciones médicas, la conciencia de su base histórica, social, cultural y estructural y los aspectos interseccionales de la opresión, la discriminación y el estigma. Si bien las diferencias de poder no son absolutamente evitables, pueden reducirse o, al menos, hacerse explícitas a ambas partes, reconocidas. Por último, la Práctica Clínica Crítica requiere comprender cómo los co-determinantes sociales, económicos y culturales están actuando en la salud de los individuos y colectivos, que estos no son un problema *natural* y, en consecuencia, que pueden ser cambiados.

Preguntas de investigación y alineación de los resultados y los objetivos

El **objetivo general** de esta tesis doctoral fue estudiar las vías factibles en entornos clínicos – analizados dentro de la sociedad en su conjunto y no aisladamente - para revelar el impacto de la vulnerabilidad, la discriminación y el empoderamiento de individuos y comunidades en la salud y cronicidad. La dimensión estructural de las desigualdades en salud no puede ni debe ignorarse al analizar estas disparidades y cómo afectan a la salud y la salud pública de las personas y a sus resultados en materia de salud, capacidad de autogestión y competencias de toma de decisiones.

La pregunta de investigación preguntó sobre "las *principales barreras y facilitadores para la comunicación en salud y, específicamente,para la obtención de información, la contratación de poblaciones de difícil acceso y la facilitación del acceso a iniciativas de educación informal en materia de*

alfabetización sanitaria dirigidas a elevar su empoderamiento colectivo e individual. "

La **barrera más importante** está relacionada con los co-determinantes más sustanciales: la clase social y todas las dimensiones que involucra, la educación y alfabetización previas, y el apoyo social y el entorno de los individuos. A nivel micro, la forma en que se está llevando a cabo la práctica clínica puede implicar la supervisión de los aspectos interseccionales de la discriminación, la reproducción de las desigualdades dentro del marco social y el desconocimiento de los aspectos históricos y culturales que influyen en las diferencias de poder dentro de la jerarquía social, la estigmatización y la marginación.

A nivel meso, el desempoderamiento de las comunidades en las situaciones superiores de vulnerabilidad, privación o discriminación supone una barrera significativa en todos los aspectos reflejados en la cuestión de la investigación, desde la comunicación en salud y el acceso a la salud hasta la participación significativa en la innovación en salud y atención social.

Por último, a nivel macroeconómico, las políticas de salud centradas en las personas y las cuestiones individuales en lugar de las condiciones estructurales y sistémicas y los co-determinantes refuerzan el desempoderamiento y la alienación de las poblaciones y personas desatendidas. Además, las necesidades básicas no se abordan y se consideran suficientemente en el marco de la salud pública y en las reformas de las políticas. Las reformas de las políticas sanitarias también pueden contribuir de manera sustancial reforzando o, por el contrario, cambiando el modelo médico tradicional y transformándose en una atención centrada en la persona y en la innovación basada en la comunidad, que debe tener en cuenta la dimensión social y estructural de las desigualdades en materia de salud.

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Las preguntas específicas de investigación trataban de desvelar cómo estas barreras **(i)** tienen un efecto en la autogestión de las enfermedades crónicas, (ii) impacto en la información de salud obtenida; (iii) influyen en sus usos y en los resultados y pronósticos de salud; y (iv) cómo los facilitadores para mejorar la autogestión de las enfermedades crónicas y la adquisición de información de salud, así como el impacto en los resultados de salud y pronóstico. .

En primer lugar, **el acceso insuficiente a** la información, considerando la falta de programas adaptados para la educación para la salud, suponen un desafío para la autogestión de la cronicidad en individuos altamente vulnerables. Además, las circunstancias materiales, la falta de recursos, el bajo acceso a esos recursos públicos, si los hay, los horarios de trabajo y las obligaciones de cuidado informal, las dificultades financieras y los problemas relacionados con los barrios y las infraestructuras también son barreras críticas.

En segundo lugar, las barreras y la situación de desigualdad y discriminación pueden causar una profunda desconfianza en las autoridades y, entre ellas, en las autoridades sanitarias como representantes de la administración pública; algunas comunidades discriminadas están histórica, cultural y socialmente excluidas y marginadas, siendo su marginación reproducida generación a generación y limitando su movilidad social. Las condiciones estructurales refuerzan su desconfianza y, en definitiva, la desconfianza, traducida en desconexión, reproducen sus desigualdades y disparidades a nivel social, económicoo sanitario. A nivel individual, los insuficientes conocimientos previos y la alfabetización/aritmética sanitaria, la falta de apoyo para una comprensión completa de la información, el rechazo de su experiencia de vida y el bajo acceso al conocimiento y a la educación informal, no formal, incluso formal. Se debe a problemas materiales y financieros (por ejemplo, los costos atribuibles al acceso a Internet no son asequibles). La naturaleza autónoma de la *autogestión de la salud* crónica es problemática y engañosa si se pasan por alto las circunstancias estructurales.

En tercer lugar, y ligado a la educación previa y a los conocimientos adquiridos, la baja alfabetización sanitaria impide obtener un aprendizaje significativo o, al menos, una rápida adaptación a la enfermedad presente y la implementación de estrategias eficientes de autogestión y afrontamiento. Además,podría haber habilidades y competencias insuficientes para traducir la información recibida en conocimiento, entonces, para traducirla en una comprensión profunda de la información que se puede transferir a acciones y aplicaciones prácticas en entornos de la vida real. Sin embargo, estas barreras son modificables: no son *naturales,*no son barreras *esenciales* e *inmutables,* no son factores constitucionales de individuos aislados de su propio contexto social. Estas barreras están determinadas social y estructuralmente y pueden ser superadas y cambiadas mientras son difíciles debido a su normalización.

La recuperación del objetivo general de esta disertación, la comprensión de las desigualdades en salud y su naturaleza estructural y socialmente determinada, y las formas en que puede ser superada revela la necesidad de una transformación profunda que debe ser alineada y emparejada con políticas capaces de poner a las personas y las comunidades en el centro. Es necesario apoyar la generación de estructuras participativas capaces de apoyar los procesos de empoderamiento, fomentar la autonomía de los pacientes y reforzar la conciencia social de los profesionales e instituciones para analizar críticamente cómo los co-determinantes sociales, culturales, económicos y ambientales de la salud y la estructura del propio campo social se entrelazan en su práctica clínica.

Fortalezas y limitaciones

Si bien las fortalezas se consideran un valor añadido importante de la presente disertación, se identifican algunas deficiencias.

En primer lugar, debe observarse y reconocerse que la calidad de los estudios muestreados es heterogénea; aunque los criterios para incluir los estudios se basaron sólidamente en las preguntas y objetivos de la investigación, y se establecieron diferentes mecanismos de control de calidad, coexisten diferentes tipos de estudios; los temas centrales varían, así como la riqueza conceptual y la contribución al campo de la investigación. En cuanto al mecanismo de control de calidad, sólo se incluyeron los artículos calificados como muy buenos y excelentes después del CASP para estudios primarios cualitativos, atendiendo a su claridad, relevancia y riqueza, y considerando cuidadosamente la literatura gris de alta calidad y revisada por pares (específicamente, disertaciones de doctorado y MsC incluidas).

En segundo lugar, la contribución variable al campo de la investigación, la extensión o formato heterogéneo y la vasta muestra incluida suponían una dificultad adicional en el análisis de la información y, además, en la construcción de teorías. Sin embargo, esta limitación se superó a través de un enfoque innovador para una meta-síntesis con una muestra considerable. Como ya se ha destacado, esta disertación abarcó una amplia muestra: se incluyeron y analizaron 103 estudios. Esta situación atípica es a la vez, una debilidad y una fortaleza de la investigación: es una debilidad por los desafíos de investigación que suponía y las dificultades metodológicas encontradas para construir líneas de argumentación, teorías de rango medio y, lo más importante, la generación de recomendaciones para la práctica, que es una de las metas y objetivos clave del presente trabajo. Es una fortaleza, también: la enorme cantidad de literatura revisada permitió una visión general integral de los mecanismos estructurales, los factores de los individuos y las comunidades que co-determinan la salud, el compromiso y el empoderamiento e, incluso, las suposiciones, creencias y posiciones de los investigadores y proveedores, transmitidas a lo largo de los estudios revisados.

En tercer lugar, y en conexión con la riqueza conceptual de la presente investigación, debe reconocerse que, debido al alcance y las limitaciones formales, se prestó poca atención a áreas problemáticas particulares y subgrupos y comunidades específicos.

La perspectiva integradora y el enfoque en la autonomía de los individuos y el empoderamiento de la comunidad para enfocar el compromiso es una fortaleza significativa de nuestro estudio que debe considerarse unida a la transparencia, honestidad y claridad de los fundamentos teóricos y de investigación y las expectativas y perspectivas de la investigadora.

Por último, pero no menos importante, la presente investigación tiene implicaciones importantes para la práctica del mundo real en entornos clínicos, de investigación y comunitarios. La ambición en cuanto a contribución social era la de contribuir a establecer una comprensión multidimensional de la comunicación y la educación para la salud en entornos interpersonales y comunitarios que se pueda aplicar a la innovación social y de salud para personas y colectivos desatendidos, capaces de superar las disparidades de salud, todas ellas situaciones injustas y evitables, promoviendo la salud a través de un enfoque centrado en la comunidad y culturalmente adaptado. **La *traducción* o transferencia del resultado de la investigación a ideas prácticas proporciona sostenibilidad y una visión a largo plazo para el presente trabajo.**

Futuras líneas de investigación

Como ya se ha introducido, el análisis de realidades específicas es el defecto más importante de la presente investigación: las futuras líneas de investigación deberían considerar la ampliación de la perspectiva y completar el presente trabajo analizando estas cuestiones aplicadas a diferentes grupos de edad y, específicamente, a jóvenes y personas mayores; si bien la investigación en ciudadanos de edad avanzada está aumentando, existe una falta de evidencia sistemática para analizar los mecanismos estructurales involucrados en la comunicación, el compromiso y el empoderamiento en salud en los jóvenes, que podrían enfrentar desafíos adicionales en la autonomía, la toma de decisiones y la autogestión teniendo en cuenta su posición en la jerarquía social y su potencial falta de independencia. Además, se requiere una atención específica desde el punto de vista del género, en particular, en lo que respecta a la queerness y las masculinidades. Otras preguntas interseccionales en torno a los cuerpos y las realizaciones deben integrarse dentro de ese análisis siendo crítico en la investigación de los aspectos de género relacionados con la masculinidad. Las enfermedades raras y los retos que conlleva tener una condición rara son otra línea de investigación que invita a la reflexión: las enfermedades raras presentan dificultades adicionales en la comunicación y validación/despido en la consulta médica, el acceso a información fiable, las alianzas de los pacientes y el empoderamiento colectivo.

Si bien se ha llevado a cabo una amplia investigación sobre la alfabetización sanitaria basada en pares y los grupos de apoyo mutuo para grupos altamente marginados y estigmatizados (por ejemplo, personas sin hogar, trabajadoras sexuales, etc.), también es necesario traducir sus hallazgos en resúmenes de mejores prácticas, casos de éxito, recomendaciones y directrices. Por último, se necesita una investigación específica y empírica de los grupos y programas de alfabetización sanitaria en línea, mHealth y de TI para comunidades desfavorecidas y empobrecidas.

* * *

En resumen, esta disertación encontró mecanismos clave, áreas problemáticas, desafíos, potenciadores y barreras relacionadas con el acceso a la atención médica, la comunicación y el asesoramiento, la autonomía, el acceso de los pacientes a la información, la autogestión de las condiciones crónicas y la toma de decisiones sobre la alfabetización y la educación en salud y el empoderamiento de las comunidades.

Aparte de las características, las relaciones y las particularidades de las organizaciones y las comunidades subalternes, contrahegemónicas y normativas/hegemónicas, los mecanismos estructurales encubiertos y no obvios subyacen a las desigualdades sanitarias y sociales.

Estas disparidades deben ser develadas y abordadas desde un enfoque sociopolítico, enfatizando y abordando directamente los entornos macro y promoviendo una profunda transformación y cambio de paradigma en las relaciones dentro del ámbito social, el sistema de atención y las políticas públicas que superen la brecha de salud de la desigualdad. Sin reconocer su naturaleza amplia, profunda, compleja y estructural, todos los esfuerzos de salud pública dirigidos a los individuos corren el riesgo de ser triviales, banales, insignificantes y sin sentido.

INTRODUCTION

THEORETICAL FOUNDATION -CONCEPTUAL FRAMEWORK

Chapter 1 is comprised of the introduction and problem statement, the theoretical foundation of the whole dissertation and also includes a brief conceptual framework, aligned with the key fields addressed during the whole research.

The first section comprises the problem statement as a brief introductory note jointly with the explicit theoretical position. Then, the second section, the **theoretical foundation** is focused on health disparities and the concept of vulnerability in light of the sociology, philosophy and intersectional theories, aimed at tracing a comprehensive characterisation of social determinants of health and the access to healthcare services, but also to education, social care or public participation. These issues will be addressed again, precisely, in the section on the conceptual framework.

Lastly, the third section, the **conceptual framework** defines the socio-ecological model used through the research, key definitions of communication and how these are applied to counselling, the role of information and health literacy in-light of the evidence, the role of the engagement – and their importance at individual and community level -, the differences between adherence and compliance, the question of self-management and self-care, the decision-making issue and, lastly, the empowerment and its characterisation.

Section 1. Problem statement

The psychosocial vulnerability of individuals and communities (and vice versa) is determined by a complex network of circumstances that should be analysed from an intersectional and relational approach. The greater vulnerability affecting individuals and communities impairs their health literacy, access to healthcare and communication with health professionals, which impacts their decision-making process and their self-management of health abilities.

The consequences of health inequalities are multiple and complex: this dissertation is focused on how these consequences impact health communication and literacy and, thus, the living experience of the diseases and the communities' health.

Social Determinants of Health (SDoH) can co-determine even constitutional factors: for instance, height might be affected by the mother's nutrition during the pregnancy; some other elements of the exposome will be present in the long-term constitution at the psycho-biological level of the individual. Individuals' resources, relationships, communities, organisations, and structural co-determinants of health disparities need to be analysed for understanding the whole picture that the complex network of co-determinants present. Health inequalities are "unfair and avoidable" situations of privilege and oppression, caused and reproduced by public policies and by lifestyle choices deeply influenced by structural factors" (Dahlgren and Whitehead 2007, 1).

Psychosocial vulnerability and disadvantage affect and impact the patient-provider communication, the ability to obtain health education and the patients' autonomy. These situations undermine the patients' skills and efficacy in decision-making and their engagement in health and self-care (Edwards, Davies, and Edwards 2009). These are also reinforced by the **traditional medical model**, which supposes a significant barrier and reluctance to the promotion of a proactive, participative and autonomous role for all patients, regardless of their circumstances (Joseph-Williams, Elwyn, and Edwards 2014). Due to their social, economic, cultural and environmental situation, some persons and communities in a case of higher vulnerability might be, as well, reluctant to be contacted by social and healthcare staff and health authorities, and thus, to be engaged in their own healthcare journey; sometimes, these groups and individuals may be even considered hard-to-reach (Duvnjak and

Fraser 2013; Shaghaghi and Aziz Sheikh 2011). This rupture between the individuals, communities, and the healthcare system contributes to its reproduction and increases their marginalisation and social exclusion, impacting their health outcomes over time.

* * *

Health, income and education interact in a complex way; specifically, social class is a major co-determinant of health – which comprises the sociocultural and the socio-economic positions, influenced by education and credentials, income, autonomy or independence in the workplace, among other factors (E. O. Wright 1983; 1992). Health and education are two very relevant dimensions for social and economic growth: the mutual influence of education and health is being studied since the decade of the 1960s (Schultz 1961; Becker 1975); specifically, the number of years of education of persons appears linked to their health expectancy and longevity (Fuchs 1979), whilst the advancements in medicine, pharmacology and biotechnology should be also taken into account as well as the change in the productive system and the role of the social planning of health systems.

Health, income inequalities and mortality have shown a complicated relation. Research evidenced that the effect of income inequality in mortality disappeared controlling the education variable – that is, once the subjects finished Secondary Education (Muller 2002). A multicausal explanation considering health, nutrition and education explains how the effects of prolonging the years of schooling could reduce adverse health outcomes (Tillmann et al. 2017). There is a significant correlation between chronic diseases and low-skilled professional categories, influenced by income (M. O'Mahony and Samek 2016). Individuals' health, education and human capital have, themselves, a significant role in Public Health. For instance, an undetermined cycle of poverty or financial crisis may suppose malnourishment of children and adults – including pregnant women – which, at medium and long-term, might reduce their productiveness of the workforce and, thus, the social mobility (Frankenberg and Thomas 2017). Besides, the income, the years of education (formal) and the access to long-life learning impact the individuals' competencies for accessing, selecting and using reliable information and acquiring new knowledge; specifically, it may affect the individuals' ability for acquiring health literacy and being able to improve their self-management of health, Quality of Life and, then, decision-making and health prognosis or outcomes. Heritability

(Bourdieu and Passeron 2008) should also be considered when analysing individuals' choices, ingrained in their own culture or sub-culture, and reproduced generation by generation. Considering also the environmental determinants, the most recent theories about the exposome, as a social, environmental and constitutional co-determinant of health (Vrijheid 2014), also reinforce the role that the early-life of the individuals and the exposition during pregnancy have in their health results over their lifespan (O. Robinson et al. 2018; O. Robinson and Vrijheid 2015; Vrijheid et al. 2014).

This dissertation also considers other situations underlying the social field and the structural circumstances related to health inequalities. Informal work, informal caregiving and reproductive work, intersections between abilities, ethnicity, culture, or age, among others, and other changing realities whose nature and impact on health need to be analysed and considered.

Research context

This dissertation also considers during its whole lifecycle the fact of **power differentials** within the healthcare system and, more important, between providers and patients. How the power differentials at the micro-social level impact the access (and lack of access) to the health system, information and decision-making is a core issue questioned throughout the dissertation and kept in-mind during the analytic process. Power differentials and positions 'occupied' by individuals within the social field, the description of mechanism able to impact on their life and life stings, and the behaviours and attitudes held by all actors – including interests, objectives and goals, influences and potential decisions in health and care – are considered jointly with the *cultural reproduction* and the transmission of norms and values.

An appropriately designed and well-tailored attention to chronic care for patients at risk of exclusion or socially excluded, traditionally discriminated groups and persons and individuals in situations of greater vulnerability has the potential to improve communities' health and, so, public health (Dahlgren and Whitehead 2007), thus, contributing to the sustainability of public health systems and welfare states and the social inclusion of discriminated collectives: health, education and income are intrinsically related. However, the progress towards health equality requires an in-depth structural reform, policy-making and empowerment of these communities; besides, the training and information available for social and healthcare professionals are scarce

and not systematised except in the scientific literature, whilst the scientific evidence is also dispersed.

In sum, despite persons in situation of higher vulnerability and/or deprivation often have poorer health outcomes, the problem is deeply ingrained in the structural conditions and framed within an ecosystem of social, economic, cultural, and environmental determinants. **Structural conditions** affect life choices, habits, behaviours, options and access to health or education. All these individual factors are co-determined by several systemic circumstances, underlying the mere appearance, being the vast majority of the individual's control. Thus, there is a need to approach this problem area from an intersectional, critical and relational perspective, considering the social class, ethnicity and cultures, material and natural circumstances, education, comorbidities, constitutional factors that may be or not co-determined by social factors, normativity and public policies surrounding the discrimination, deprivation and lack of access to appropriate health and social services.

To analyse all the co-determinants involved in health inequalities is out of the scope of the present dissertation. Instead, **the contextual research framework focuses on how a complex and multidimensional set of factors and circumstances,** permanently changing nowadays, interact and impact individuals and communities' health, engagement, and empowerment. Thus, this dissertation aims at addressing:

- A multidimensional framework for analysing and interpreting how the social vulnerability influences the counselling, access to information and health literacy, self-management of chronic care, decision-making, patients' autonomy and communities' empowerment; then, unveiling the intersections and factors involved in health disparities and the formal factors that may entail the individuals' and communities' vulnerabilities.
- Health communication dimensions, including the intrapersonal and interpersonal micro levels, as well as the factors related to the efficacy, acceptability or engagement in the communication process
- The engagement mechanisms in self-management and health decision-making of individuals; and the engagement mechanisms of deprived and traditionally discriminated communities that can lead to their empowerment and societal change, including culturally tailored care, patient-provider communication, efficient and ethical recruitment and implementation of

health literacy programmes and mutual support groups, co-production of health interventions, reforms, and policies.

Theoretical position

Qualitative research implies a more significant contribution by the researcher in terms of subjectivity and creativity; consequently, biases and pre-assumptions may be present. The role of the qualitative researcher and the nature of the re-interpretative and the synthesis works makes the neutrality a non-realistic goal: the explicit recognition statement of theoretical – thus epistemological and ontological – positions assumed by the research when conducting, interpreting, and producing the study is required and even constitutes a foundation of rigour and transparency.

This PhD dissertation is intended and aims at being a critical work, able to tackle health inequalities from their structural foundations, relying on relational sociology theories and intersectional frameworks further detailed in the next sections and, precisely, in its Section 2 on Theoretical Foundations. Whilst this dissertation is not 'militant' and is not aimed at advocacy, the recognition of the structural and socially co-determined nature of individuals' habits, behaviours and decisions is present; thus, health disparities cannot be reduced to individual disparities rather than systemic inequalities (Katikireddi et al. 2013). and also, the traditional exclusion, discrimination and even oppression of specific collectives, and the situation of the privilege of others (Crenshaw 2019). The question of the power differentials is present within the fundamental research from its design and is also a central problem area in analysing social and health disparities and the interaction of different actors within the social field. The assumptions about life, death, virtues, morality (Turner, 2000; 139-140) and the Ideology and hegemony (Mannheim 1993), and its relation to the power differentials, the hierarchy of different actors and the relationships between subjects, societies and communities are taken as a whole from a relational and intersectional perspective.

The **gender** perspective is implicitly present during the whole research and through the dissertation. Masculinities and femininities are taken into account and interpreted in light of intersectional feminist theories, considering the gender differentials and the role of sexism in healthcare and within the health systems, but also other manifestations of sexism and different types of oppression (e.g., classism, credentialism, ageism, ableism, mentalism, among others, and their interrelations and, so, intersections). In order to respect the gendered realities and lived experience of all research participants in the sampled studies, plural forms are generally used, avoiding the dichotomy *she/he, feminine/masculine*, except for citations and for those cases in which the self-identification with both traditional genders (cis-gender individuals) is relevant and pertinent for understanding the results, and well-accepted by the participants.

Lastly, this dissertation takes the notion of the **social class** instead of the Socio-Economic Status (SES), as a global dimension. Using the social class as foundation and theoretical position permits us to consider the aforementioned SES, but also the socio-cultural position, the nature of the job and the position within the workplace, the qualifications and education, and the autonomy and social perception of each individual. In other words, the social class as key notion reinforces the related socio-economic-cultural complexity and maintaining the analysis of its consequences at the relational level. In-line with the Theories of Reproduction, the social class is a foundation and a crucial criterion for understanding the socio-political and sociocultural changes surrounding the societal change – i.e.., the changes in populations' health, literacy, employment, works and jobs, and, in sum, the whole heterogeneity constituting the productive system of a society from its own structure.

Section 2. Theoretical Foundation: Health disparities and vulnerability

The first section is focused on the social determinants of health disparities; secondly, how these social determinants of health impact the care (received and self-care) and health outcomes; lastly, the concept of 'vulnerability' is examined.

Social epidemiology: Social determinants of health disparities

Health and Illness

Giddens (1991) characterises the **reflexibility as a characteristic of modernity**; this is, the fact that individuals reflect about themselves, their choices and their life - thus, their past and their future - constructing their identity/ies across different institutional - so, material - settings during their life cycles. Our biography reflects and reflexively organises a flow of social and psychological information about all potential ways of life, and the self-exploration process produces a negotiated self-identity.

Nowadays, *Illness* is opposed to the *Health* idea. Health as an ideal – or, at least, an acceptable minimum – state of wellbeing is equated with *normality* and *illness*, *disease* and *disorder* crystallise in the diagnosis, articulated through the *symptom*. The alignment of *Health* and *normality* was not always this way.

The definition of *normality* – a concept far from the current Health Idea – was a mere landmark until the 18th century: *normality* was implicit within the medical reflection (Foucault 2015). In the 19th century, physiology took the place of the classificatory medicine (Foucault 2015, 23-44) and the State turns responsible for (a) maintaining the social order; (b) assuring the economic growth, and (c) safeguard the Public Health. Thus, Health, Order and Welfare are the pillars sustaining the State after the Industrial Revolution (Estany and Puyol González 2016, 208).

Rational conduct of political affairs in modernity is needed for detailed information about the characteristics, evolution, and transformation of society. After the French Revolution, paraphrasing Foucault (1976), two myths – as the author names these - enhanced: (1) the medicine needs to take its place in the public space and (2) illnesses can disappear through education and through establishing political solutions to poverty:

> The years preceding and immediately following the Revolution saw the birth of two great myths with opposing themes and polarities: the myth of a nationalized medical profession, organized like the clergy, and invested, at the level of man's bodily health, with powers similar to those exercised by the clergy over men's souls; and the myth of a total disappearance of disease in an untroubled, dispassionate society restored to its original state of health.
>
> (Foucault and Sheridan 1976; 31-32)

Philosophy and Sociology of Health encounter a common ground in the *diagnosis* construct. The *diagnosis* itself is a construct for defining a pathology and establishing a treatment. Although a diagnosis could validate a patients' perceptions and giving their experience a name, the diagnosis pathologises the everyday. Diagnosis, in this context, should be understood "as a potent social instrument underlines the authoritative role of medicine and doctors" and, also, "a cultural phenomenon, a system of identification and categorization, embedded within it cultural beliefs and meanings about the self and others, identity, normalcy and deviance, health and infirmity, and the root of the definitional struggles overdiagnosis is the difficulty in discerning, interpreting and translating the meaning of symptoms" (Ebeling 2011)

> [The symptom] In its existence as pure phenomenon, it is indissociably the only nature of the disease, and the disease constitutes its only nature as a specific phenomenon. When it acts as a signifier in relation to itself, it is therefore doubly signified: by itself and by the disease, which, by characterizing it, opposes it to non-pathological phenomena; but, when taken as a signified (by itself or by the disease), it can receive its meaning only from an earlier act that does not belong to its sphere: from an act that totalizes and isolates it, that is, from an act that has transformed it into a sign in advance.
>
> (Foucault and Sheridan 1976, 91)

That is the power of diagnosis resting "within the social power to name a disease, to define and frame symptoms as pathologically indicative of a disease state, to codify what is normal and what is deviant, and to provide social order to chaotic bodies" (Ebeling 2011).

Health and health disparities cannot be reduced to willingness, habits and behavioural change (Katikireddi et al. 2013). Besides the currently in-place traditional medical model which emphasises the individuals' outcomes without paying sufficient attention to all bio-psycho-social issues and factors affecting each patient as a person and a member of a wider community and society, a distorted notion of 'empowerment' is being popularised by the mass media and assumed by the society. This distorted notion often crashes against the vivid lived experience of patients and survivors of severe chronic illnesses, leads to a struggle for meaning that challenges patients' emotional well-being and disrupts the actual research results.

As broadly disseminated in mass media and social networks, *positive thinking* feeds a distorted notion of 'empowerment' that undermines the right to suffering and, ultimately, increases the sense of loss of control of the patient, being confronted with the recurrence, the metastasis and mortality rates. However, as Willig (2011) noticed, it seems that cancer patients are compelled to accept their own (and sometimes sole) responsibility and declare ownership of their cancer. Then “the diagnosis and the meaning of the disease name is connected by the self and reflect a sign of moral failing by the patient.” (Willig 2011).

> Such an ideology focuses on individual responsibility (for health, for success, for employment, for access to opportunities) and elides the influence of corporate forces and the political economy. Such an ideology constructs cancer as an opportunity to demonstrate one’s superior personal qualities including optimism, resourcefulness and resilience but does not allow for expressions of anger, sadness or hopelessness, and it does not encourage political action to tackle the environmental causes of increasing rates of cancer in the USA.
>
> (Willig 2011)

These considerations could be extended to several diagnoses, to a great extent, those illness conditioned by lifestyle, habits and behaviours as long as ‘health’ and ‘illness’ are in the core of the moral constructions held by the occidental societies and express much more than mere diagnosis and medical conditions. ‘Health’ implies essential assumptions about life and death emerging from structural and cultural conditions able to configure the power relationships between subjects and societies (Turner, 2000; 139-140)

> The setting up, in the course of the classical age, of this great bipolar technology- anatomic and biological, individualizing and specifying, directed toward the performances of the body, with attention to the processes of life characterized a power whose highest function was perhaps no longer to kill, but to invest life through and through. The old power of death that symbolized sovereign power was now carefully supplanted by the administration of bodies and the calculated management of life.

The interrelation of different processes – far from triumphalist interpretations on human and scientific progress – has led to these changes in occidental medicine; processes also linked to power relations in the society and between individuals. These processes also determine the research agenda. For instance, secularisation, new scientific theories and evidence on health, the differentiation of physical and mental disorders – and also of functional and somatic diseases – and the change of paradigm in medicine mediated by all aspects as mentioned earlier: traditional physiology gave way to classificatory medicine and the current evidence-based practice.

Moral meaning, health and Ideology

The diagnosis itself carries connotations concerning the aetiology and the patients' responsibility for 'bringing on' the condition and the contagion, that might turn in moral connotations: those may interfere during the counselling, decision-making process even in self-management guidelines and clinical advice; however, the most destructive ones are related to the societal perceptions concerning the stigma through the connexion with immorality-diagnosed illness or the moral failing of patients self-managing their own disease and, then, not reaching the optimal outcomes. For instance, one implication of this construction is the expectation that the cancer patient should accept this responsibility and declare ownership of 'their' cancer, even a "war" against cancer: Word choice is not neutral and impacts the care received. Giving a disease moral meaning is a punitive process that positions those diagnosed with the disease as culpable, as tainted, as shamed (Willig 2011).

Nowadays, Health is understood as a perfect equilibrium of wellbeing and absence of illness, defined from the negation of the disease; Health also has moral connotations and obligations and progressively occupy our whole lives as a sort of 'ethical imperative'. This problem has been addressed by identifying three major sequences of socio-economic change during the 20th century: "productionist" - health as the maintenance of the workforce and reproduction; the State begins to deal with health -; "communitarian" – linked to the welfare state; element for cohesion and social inclusion; rights of citizens; family and community medicine model; and "consumerist" – the medicine is consumed. Even though these sequences coexist throughout the century, Pickstone (Lupiáñez Villanueva 2009, 35–36) points out that there is a certain temporal order between the three. In this sense, the first two stages would encompass the birth and heyday of the biomedical model, while the last stage may be the beginning of criticism and questioning of the biomedical model.

From this consideration of Health as a moral value emerges the Myth of the Healthy Man, strongly anchored in personal responsibility; life is fully devoted to health, and not the other way around. The indefinite medicalization of life coexists with inequity in health access; Hegemonically prevails the economic-business perspective in health management. The consequences, these two tendencies are not opposite: they respond to the same biopolitical logic that maximizes the potentials of some to the paroxysm and relegates the vast majority of the world's population to death (Anna Quintanas en (Estany & Puyol González, 2016)

Research shows how to approach health and health outcomes only by diagnosis, recommendations and/or by changing the individuals' behaviours and their ‘bad habits’ cannot overcome the historical, current and factual health inequalities: most important ones are **gender, ethnicity and socio-economic position**, even more, class (Katikireddi et al. 2013). **Health inequalities are considered structurally determined, thus cannot be overcome by individual action – or, at least, it** cannot be genuinely mitigated by personal choices and behaviours. Considering the experiential and vivid experience of patients’ this dissertation is approached from an intersectional perspective regarding health and social inequalities; social determinants of health, analysed in the next section, are also interpreted in light of intersectional theories, further explained below.

Social determinants of health and social determinants of care

Human Capital Theory, policies background and contextual considerations on health and education

The European Commission defines the Human Capital as the productive potential of individuals and groups founded in their “Knowledge, skills, competences and attributes embodied in individuals that facilitate personal, social and economic well-being” (VAREIKYTĖ and BABRAUSKIENĖ 2016). The Human Capital Theory appeared in the 60s decades as a neo-liberal, functionalist and descriptive mathematical model for explaining the economic growth in occidental society, assuming the linear progress model. The linear progress model (Vannevar 1945) was furtherly developed in the U.S.A. during the II World War – and, so, linked to the Manhattan Project - which reflects the idea of a continuous and unending progression of the society based on the endless frontier of progress as regards the science and technology.

> Science can be effective in the national welfare only as a member of a team, whether the conditions be peace or war. But without scientific progress no amount of

> achievement in other directions can insure our health, prosperity, and security as a nation in the modern world. [...] Basic scientific research is scientific capital. Moreover, we cannot any longer depend upon Europe as a major source of this scientific capital. [...] Clearly, more and better scientific research is one essential to the achievement of our goal of full employment. How do we increase this scientific capital? First, we must have plenty of men and women trained in science, for upon them depends both the creation of new knowledge and its application to practical purposes. Second, we must strengthen the centres of basic research which are principally the colleges, universities, and research institutes. [...] The most important ways in which the Government can promote industrial research are to increase the flow of new scientific knowledge through support of basic research, and to aid in the development of scientific talent.
>
> (Vannevar 1945)

The optimistic perspective on progress, science and an educated society, as well as the socio-political and geostrategic environment arising at the end of the war, are reflected in the citation above. *The Investment in Human Capital* (Schultz 1961) is the founding chapter of a theory founded on a ground tradition and academic research – as grounded as their critiques -, nowadays ramified in several derived systems. The HCT suggest that the public and private investment in Health and Education – thus, the government, enterprises and entrepreneurs, and individual investment – will lead to an improvement of the labour factor and a greater productive capacity at the national level. This productivity could also be measured through mathematical models, similarly to the labour and the physical and material capital. (Schultz 1961; Becker 2008)

Although the model for explaining the human progress exposed by Vannevar Bush (1945) and its relation with national prosperity and welfare cannot be considered a seed for the Human Capital Theory itself, it explains and reflects the intellectual and cultural background in which it arises. The passage below, relatively recent, written by one of the most important academics, also reflects the linear progress model:

> Economic growth closely depends on the synergies between new knowledge and human capital, which is why large increases in education and training have accompanied major advances in technological knowledge in all countries that have achieved significant economic growth.
>
> (Becker 2008)

The HCP analyses the labour and its role within the classical analysis - land and capital (Foucault 2009) - states that the wage is, simply, a type of income, assuming equal opportunities for all individuals and do not consider origin, gender, ethnicity and other historical, structural and material determinants. If inequalities are superficially recognised, the possibility of solving these structural inequalities is preconceived[1].

Later, in the 80s, after the Oil Crisis (1973), Becker (1975) started the major theoretical foundation of the HCT, which will result in a vast range of reformulations and new derived approaches, such as the various theories of competencies and their breakups. Becker defined workers as *Entrepreneur of the Self* (Foucault 2009; Becker 1975), raising questions about the significance of work and labour as a passive factor for producing during the twilight of the twentieth century and its systemic crisis, wars and hyperinflations. A few years after, Mincer established and summarised the most important thesis of this theory: (a) the correlation between schooling, non-formal education (e.g., life-long learning), health and wages or investment incomes, analysed under the same conditions (Mincer 1994; 1981). To analyse the socio and geopolitical context of Becker and Mincer's works and, in general, the HCT, is out of scope in this dissertation. However, it is relevant to analyse society and market outside its own context and the rise of the prosumer concept as long as it explains the theoretical assumptions that emerge from the *Empowerment as a locus of control.* Likewise, the man that insofar as consumers is a producer on the basis of the capital he has at disposal and produces his own satisfaction being a partner of the government and the owners.

Functionalist theories and codeterminants of Health

The socioeconomic status (SES) and Education are two dimensions of co-determinants of Health frequently used in the literature – being that underpinned within functionalist theories. The socioeconomic status is measured by the incomes (derived from the wage or investment) and other assets. Income is the most studied socio-economic indicator due to its usability and capability for assessing the material resources available for individuals, families and groups and their interaction or influence on their health.

Another variable, easily quantifiable and measurable, is Education. (Galobardes 2006). "The number of years of schooling, rather than level of income, emerges as

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[1] Despite that, and despite the limited perspective on the society studied and all never-denied biases, researchers demonstrated the social, cultural and economic advantages that the investment – individual, collective or governmental – supposes for the improvement of Health and Education (Frankenberg and Thomas 2017; M. O'Mahony and Samek 2016; Papageorge 2016).

the surest correlate of good health” (Fuchs 1979), even recognising the critical role of the medical advances and biotechnologies, the change in the productive system and the role of the public and social planning of Health. The links between Health and Economic development and growth are variable: while in the long-term public health improves with the economic development, if the economic growth primarily increases the income “of already affluent groups “ and if the healthcare system remains severely underfunded, the links diminish or disappear (Dahlgren and Whitehead 2007, 38).

Improved health is an important determinant of economic growth, as it increases labour productivity, labour supply, educational achievements and savings. This perspective, of seeing improved health as a factor promoting economic growth, is further reinforced by the high costs to society and business of poor health p.41

While causes of good health are multiple, as it will be furtherly explained in the following sections, health, nutrition and education are strictly related since early childhood (Frankenberg and Thomas 2017). According to a recent Mendelian randomisation study, more years of education are associated with fewer coronary diseases (Tillmann et al. 2017). This research used data from two international consortia - C ARDIoGRAMplusC4D and SSGAC – producing 112 studies and a total sample of n=543,733 involved patients living in HICs (High-Income Countries). Specifically, genetic factors and predisposition and 3.6 additional years of formal education are associated with a one third lower risk of coronary diseases.

> Firstly, analyses of natural experiments have compared mortality before and after changes to compulsory schooling laws—for example, by looking at mortality rates in countries before and after the introduction of national legislation that increased minimum education. [...] Our mendelian randomisation analyses found genetic support for the hypothesis that longer education plays a causal role in lowering the risk of coronary heart disease to health benefits.
>
> (Tillmann et al. 2017)

Education is, undoubtedly, a social determinant of health. As it will be explained, Education - and, most specifically, credentials - determines the type of job, the wages, the access to information and the competencies regarding its critical interpretation, and conditions the maximum potential of health literacy to be reached by a subject.

Galobardes (2006a) explains that education is a frequently used indicator in epidemiology and its historical origins are in the Weberian theory. Education can be measured as a continuous variable (years of completed education) or as a categorical variable (qualifications and milestones); it is easy to measure and can be self-assessed by research subjects.

Competencies obtained during the education will determine his/her cognitive functioning and their opportunities for accessing to more opportunities of long-life learning and formal higher education (Béduwé and Planas 2003; Planas Coll and Casal Bataller 2003). Thus, a particular person's education in a closed socio-cultural system reflects the heritability of credentials and socio-cultural status from the family to adulthood. Then, it could predict – to some extent – the future employment, incomes, and assets obtained and, consequently, determine the material, intellectual and symbolic capital (Vallina Acha 2015). Another used variable is housing tenure and conditions for measuring the material aspect of the socioeconomic position. Lastly, occupation also represents the Weberian notion of SEP and reflects a person's social standing, income and intellect – and, of course, credentials and education obtained. Turning back to Education, it must be noticed how it captures the transition from parents' – and here it is relevant to briefly capture the theories on reproduction – and how the SEP and Education are determinants for future employment and income.

However, these measures cannot reflect the whole set of co-determinants of Health, precisely, those referring the social environment and cultural background and how the material and social conditions determine the health expectancies and the prognosis of the disease. Additionally, weak health in childhood limits educational attendance and could predispose to adult disease.

Health disparities and Social determinants of health

The analysis of health disparities and inequalities is an inter-disciplinary matter of research, merging political science, social sciences and humanities with classical epidemiology, health behaviour and public health fields. The research into health inequalities research and disparities research are mutually interrelated. As Figure 1 shows, Health inequalities research seems to have a more UK/European tradition, and it adopts a critical perspective on inequality, focused on policy-focused or geographically scoped approaches, concerned about work-related or migrant health, among other issues. Economic approaches and reflection or measurement of inequalities are common issues on both sides. Health disparities research is mainly conducted in the USA, providing greater insight on cancer disparities and other major chronic conditions, highly prevent, as well as to nurture the administrative reporting (Collyer and Smith 2020).

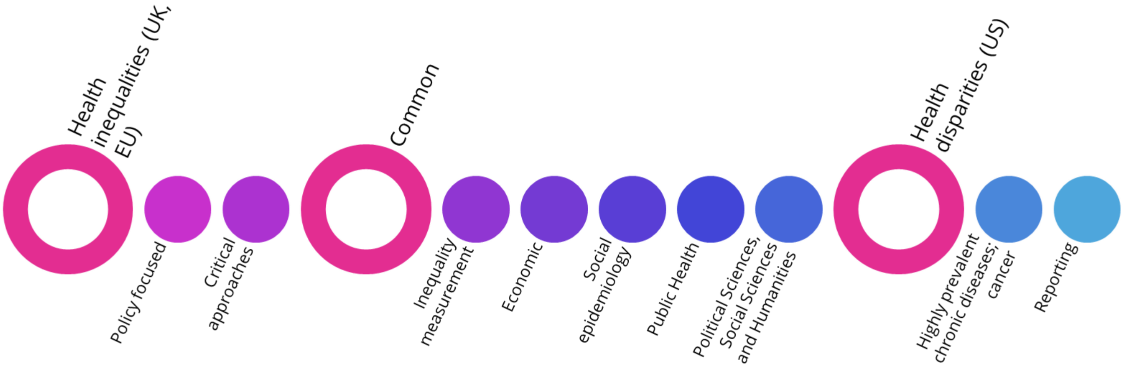

Figure 1 - Research differentials due to socio-cultural geographical coverage

Social Determinants of Health – henceforth, SDoH – is a term introduced in the 70s decade. On the other side, **Health Disparities or Health Inequalities** (HI) refers to different health status, outcomes and prognosis when comparing different groups of persons. SDOH and HI should not be used interchangeably (Graham, Kelly, and NHS Health Development Agency 2004): HI results from the different resources distribution in a socio-cultural-political system, and SDOH includes all biological and non-biological influences and risk factors as well.

> This was a perspective that quickly found its way into debates about public health policy. An early and influential example was Canada's Lalonde report, credited as being the first government report to identify factors other than the health care system as driving population health (Lalonde 1974). Its New Perspective on the Health of Canadians prepared the ground for the Health for All (HFA) charter of the late 1970s, which in turn stimulated the World Health Organization (WHO) strategy of HFA in 2000 (WHO 1981, 1985). Since then, a social determinants approach has gained widespread acceptance as the appropriate framework for developing and delivering public health policy.
>
> (Graham 2004)

Causality is intricate and extensively discussed in the field of Philosophy of Science. Terms and concepts referring to determination – even co-determination – and constraints explicitly suggest causality. In epidemiology, the debate on causation has a long tradition behind it[2] (Jordi Vallverdú 2016). Causation and causality need a number of principles and factors susceptible to be observed and measured and these cannot be quantitatively reduced to a functional and objective algorithm. These principles are:

(1) Strength of the association;
(2) Consistency, likewise, if it "has been repeatedly observed by different persons, in different places, circumstances and times" (Bradford Hill 1965, p.296 cited by Jordi Vallverdú 2016, p.103);
(3) Specificity of the association, considering its invariably too;
(4) Temporality the temporal relationships of the association;
(5) Biological gradient if the association reveals a biological gradient or dose-response curve;
(6) Plausibility: if the causation is biologically plausible;
(7) Coherence, or if "the interpretation of our data should not seriously conflict with the generally known facts of the natural history and biology of the disease" (Bradford Hill 1965, p.298 cited by Jordi Vallverdú 2016, p.103); and
(8) Experimental or semi-experimental evidence.

Susser[3] (Jordi Vallverdú 2016) reduces these principles to three: association, time order, and direction, in an ascending hierarchy. Given the complexity of the social structures, the epidemiological models and systems models for causal inference are increasingly complex as well (Jordi Vallverdú 2016, 110–11)**;** for instance, macro determinants studied by the social epidemiology should be considered in light of communities' risk factors and actual organisations related to the communities (meso-level), as well as the individuals' risk factors (exposition, behaviours, etc.), physiological/constitutional and molecular risk factors (micro-level and microscopical determinants). Structural determinants escalate even more the aforementioned complexity: culture and sub-cultures, economics and politics, policies, axis of inequalities) and intermediate (material resources, psychosocial factors, availability and access of healthcare services, etc.). Moreover, considering the complexity to establish a relation of "determination" between social factors and

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[2] Vallverdú (2016,p.103) makes reference to (Bradford Hill 1965) titled *The environment and disease: association or causation*?. A PDF copy is available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1898525/?page=1

[3] Specifically, Vallverú cited Susser, M. (1991). What is a Cause and How Do We Know One? A Grammar for Pragmatic Epidemiology. American Journal of Epidemiology, 133(7), 635–648. https://doi.org/10.1093/oxfordjournals.aje.a115939

health outcomes can result difficult even impossible; that is why, in this dissertation, we opt for the naming “co-determinants”: determinism implies invariability of results rather than correlation, but our interaction with our social field and sphere is very complex and, in terms of health outcomes, also mediated by biogenetical, physiological, constitutional or environmental factors (Estany and Puyol González 2016, 63). **Codeterminants will be explored in the Section on Vulnerability; however, codeterminants of health might be, among others,** (Jordi Vallverdú 2016)**: (i) structural,** including the socioeconomic and political context (macroeconomics, labour market, the welfare state and care models; culture and values; social class, not restricted to the socio-economic status or SES (Galobardes 2006; Goldthorpe 2012), gender, age, ethnicity, territory; axes of inequality (Graham 2004); and (ii) **intermediate** such as groups and individuals’ material resources (labour, employment, work conditions; informal care, informal jobs, income; housing; residential and local environment), psychosocial factors, behavioural and biological factors and the access to the healthcare services.

Walking the line: Vulnerability as a gradation

Social vulnerability is a term frequently used for describing the lack of resilience capacity of an individual or society to natural hazards and disasters (Adger 2006; Kuhlicke et al. 2011). In this context, “vulnerability is a product of specific spatial, socio-economic–demographic, cultural and institutional contexts imposing not only specific challenges to cross-country research concerning social vulnerability to flooding but also to attempts at assessing social vulnerability in general” (Kuhlicke et al. 2011). In this dissertation, we interpret the concept ‘**vulnerable groups’ as all those traditionally oppressed, discriminated or marginalised, such as, but not restricted to, minorities, including racialised groups, deprived communities or sexual minorities, among others.** ***Vulnerability*** is being understood as the result of specific socio-economic, demographic, cultural, institutional, spatial and environmental contexts(Kuhlicke et al. 2011) encompassing the susceptibility to hazard and, then, the diminished capacity to cope and/or to adapt. Thus, *vulnerability* is opposed to *resilience*, or the capacity of social, economic, and environmental systems for coping with hazardous events, disturbances, and adverse events, being able to respond and to maintain their basic functions (or identities, structures, etc.), at least to some extent of functionality, transformation, and adaptation (Field et al. 2014, chap. 11).

Traditionally discriminated, marginalised, or excluded communities are considered vulnerable in this article, as long as the historical power imbalance might diminish the community's ability and individuals to cope with adverse events due to structural reasons. For instance, included vulnerability conditions considered are isolation and lack of access to healthcare and resources, rural communities, youngest and oldest persons (ageism), persons with diagnosed with mental disorders, persons with disabilities or functional divergence, impoverished individuals and communities, or ethnic/racial minorities due to historical and structural discrimination and oppression. **This dissertation is aligned with an intersectional perspective, viewing all these disparities systematically and socially determined and acquired in the social interaction, reproduced in such a way that various forms of inequalities operate together, exacerbating each other** (Cooper 2016; Crenshaw 2019)**.**

While all individuals and communities are, to some extent, vulnerable, as long as all are exposed to potentially hazardous or adverse events, or ‘risks’/’emergencies’ (e.g., those determined by macro-economics, or by environmental determinants and climate change), the situations of higher vulnerability will severely affect health. Being a gradation, the impact on health or, in general, on living conditions will be higher than the impact for lower vulnerability situations; thus, vulnerability is a gradation relative to the gradation of risk (Figure 2).

Figure 2 - Relation between vulnerability and resilience given risks, emergencies and, in general, adverse actual or potential events

Both risks and vulnerabilities are given by a complex network of environmental, social, and physiological co-determinants (Figure 3).

STRUCTURAL CO-DETERMINANTS

- local level of economic development
- income inequality and poverty
- public health infrastructure
- physical infrastructure and quality of the infrastructure (e.g., electric power)
- transportation
- quality of governance
- gross domestic product
- worker protection
- among others

COMMUNITY CO-DETERMINANTS

- nutrition
- prevalence of chronic diseases
- values, conformity, norms
- historical oppresion/hegemony

INDIVIDUAL CO-DETERMINANTS

- socioeconomic and sociocultural status
- social class
- origin and administrative status
- sex and gender, expression, identity and orientations
- ethnicity and racialisation
- rural/urban
- appearance
- abilities and functionality
- constitutional factors: age, genetics, biological sex, etc.

ENVIRONMENTAL DETERMINANTS

- Mediated by social determinants
  - geographic location
  - climate stresses
  - drought
  - Coastal residents
  - urban heat islands
  - urbanization, urban areas
  - air pollution
- Mediated by individual determinants
  - older or very young age
  - comorbidities
  - low level of social support
  - housing
  - air condition/heat
  - low socioeconomic status
  - job and occupation

INTERSECTIONS

- social,cultural and economic codeterminants, situations of privilege and oppresion and discrimination interacts in complexity with environmental determinants, at macro, meso and micro or individual levels.

Figure 3 - Co-determinants of vulnerability and resilience

Class backbones not only the material distribution but also - and precisely by virtue of this - the interaction between individuals, groups and communities and the possible ways of relating. The class criterion is considered of great relevance when it comes to analysing the differential choice of people and not only in a unidirectional "determination". These differential choices in health and health-related habits and behaviours are shaped by class and other factors considered within a general intersectional framework in a complex and multidirectional way. It is worth highlighting, once again, the social reproduction of the habits as well as the social status: these habits and behaviours, transmitted and reproduced by the family, scholarly system, and healthcare system as well as by all structural determinants, would, to some extent, increase the risk of, for example, certain chronic diseases. The class-race-gender system is one of the most important the heritability social class, culture, norms, values and customs, and the social status of the immediate community or group (Bourdieu and Passeron 2008; Crenshaw 2019).

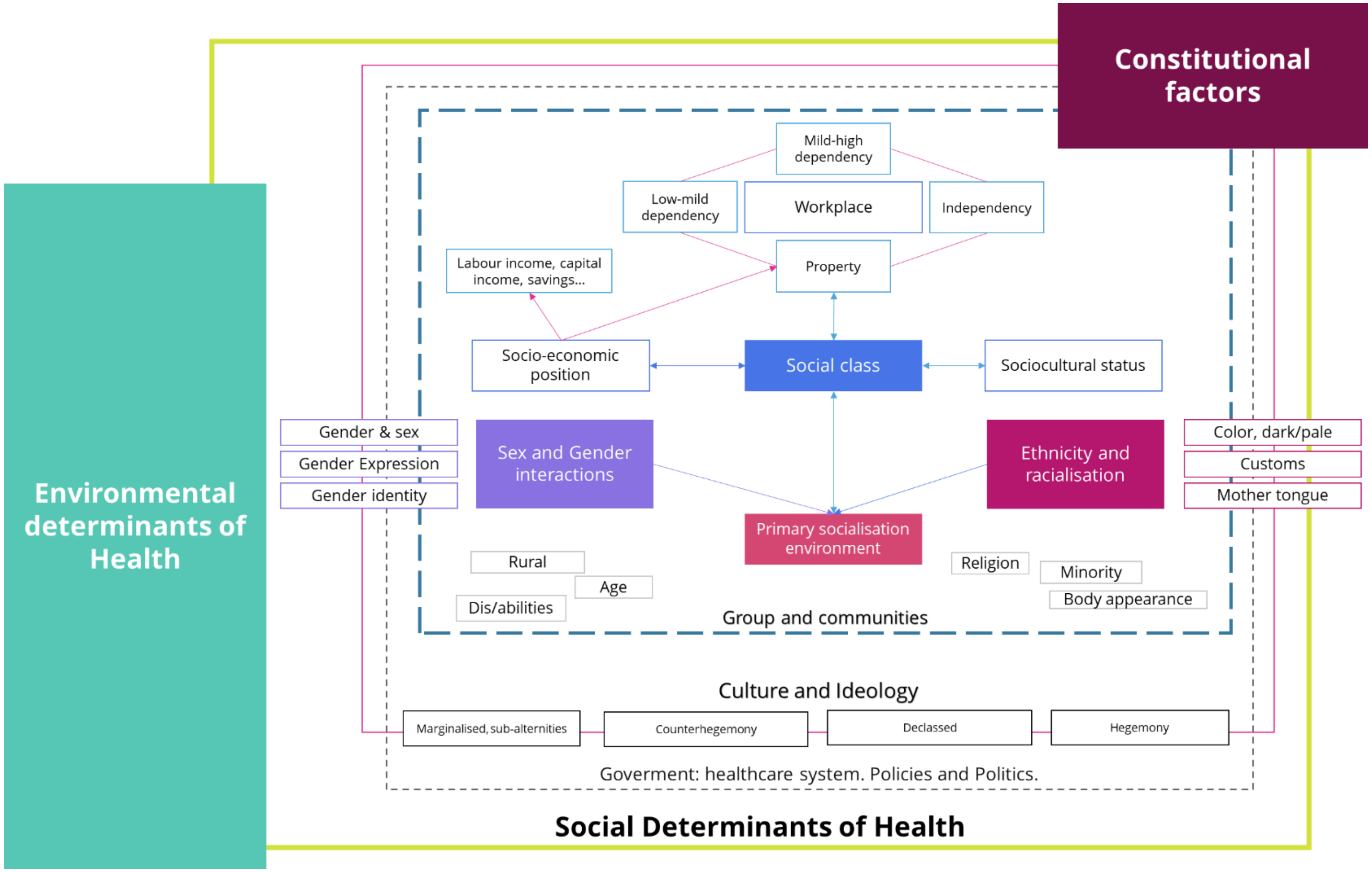

Figure 4 - Elements for a multi-dimensional and intersectional theory of co-determinants of health and chronic diseases

The Figure X summarise some social co-determinants of health, emphasising the role of the class and the social position and status of the community or group; however, gender, sex, ethnicity, race, appearance, functionality and dis/ability, age, geographical location and other situations of potential dis-privilege, even oppression, able to isolate individuals and communities leading to a situation of insecurity, marginalisation, discrimination and/or stigma affecting their social, cultural or economic outcomes and, then, their potential health outcomes and prognosis. Environmental and constitutional co-determinants are also considered. These co-determinants can determine the groups' and individuals' capacity and abilities for coping with adverse events and impact the access to healthcare, social care and administrative services, and their competencies for accessing and selecting evidence-based and reliable information, education and peer support.

'Vulnerability' affects everyone in a specific socio-political system and denotes a dimension opposed to 'resilience'. Vulnerability' is also referring to the integration into the healthcare system because of ethnic/racial, geographical, particular health characteristic or any other factor that puts members of those groups or communities at risk for not obtaining necessary care or for threatening to achieve better or good health outcomes (Flournoy 2011). Thus, the 'vulnerability' is defined as a gradient for evaluating the effect and impact of adverse events and living conditions and health considering, as a background, the health inequalities as mentioned earlier and all co-determinants.

Section 3. Conceptual framework and literature review.

This section is comprised by the conceptual framework and definitions of key concepts utilised within the research and, specifically, reflected in the Chapters 3, 4 and 5 on analysis' results, discussion, and recommendations for practice.

Socioecological model

Besides, the **social determinants of health**, as characterised by Dahlgren & Whitehead (Dahlgren and Whitehead 2007), for researching and intervening in the community are taken into account: the consideration of social determinants of health determines a **typology and process** for tackling social inequalities in health research, care and innovation (Edwards, Davies, and Edwards 2009). Concerning participation, also the classic **Ladder of Citizen Participation** (Arnstein 1969) further described in the section on *Community engagement,* is integrated jointly with more modern approaches for planning and executing patients and public engagement.

The socioecological model (McLeroy et al. 1988) distinguish 5 dimensions:

Figure 5 - Classic socioecological model by McLeroy et al., 1988

However, the classical formulation does not explicitly allocate structures and systemic determinants, neither Ideology (thus, hegemonic ideology or systems). Ideology should be briefly described here, in-light the previous theoretical foundation insights, considering Mannheim's characterisation of total Ideology and particular ideology; the **particular ideology** is implied when we explicitly show our sceptic perception about the ideas and representations that others are presenting. Contrasted, the **total Ideology** is referring to the Ideology of an age, a concrete historic-social group (e.g., a social class) and the structure of the mind of this epoch or of this groups (Mannheim 1993) and, in particular, the hegemonic construction of the reality. Thus, hegemonic ideology, structural determinants and systemic elements should be considered as well (Jordi Vallverdú 2016)**.**

The rainbow model (Dahlgren and Whitehead 2007) comprises all these elements. The following figure schematises Dahlgren and Whitehead's model:

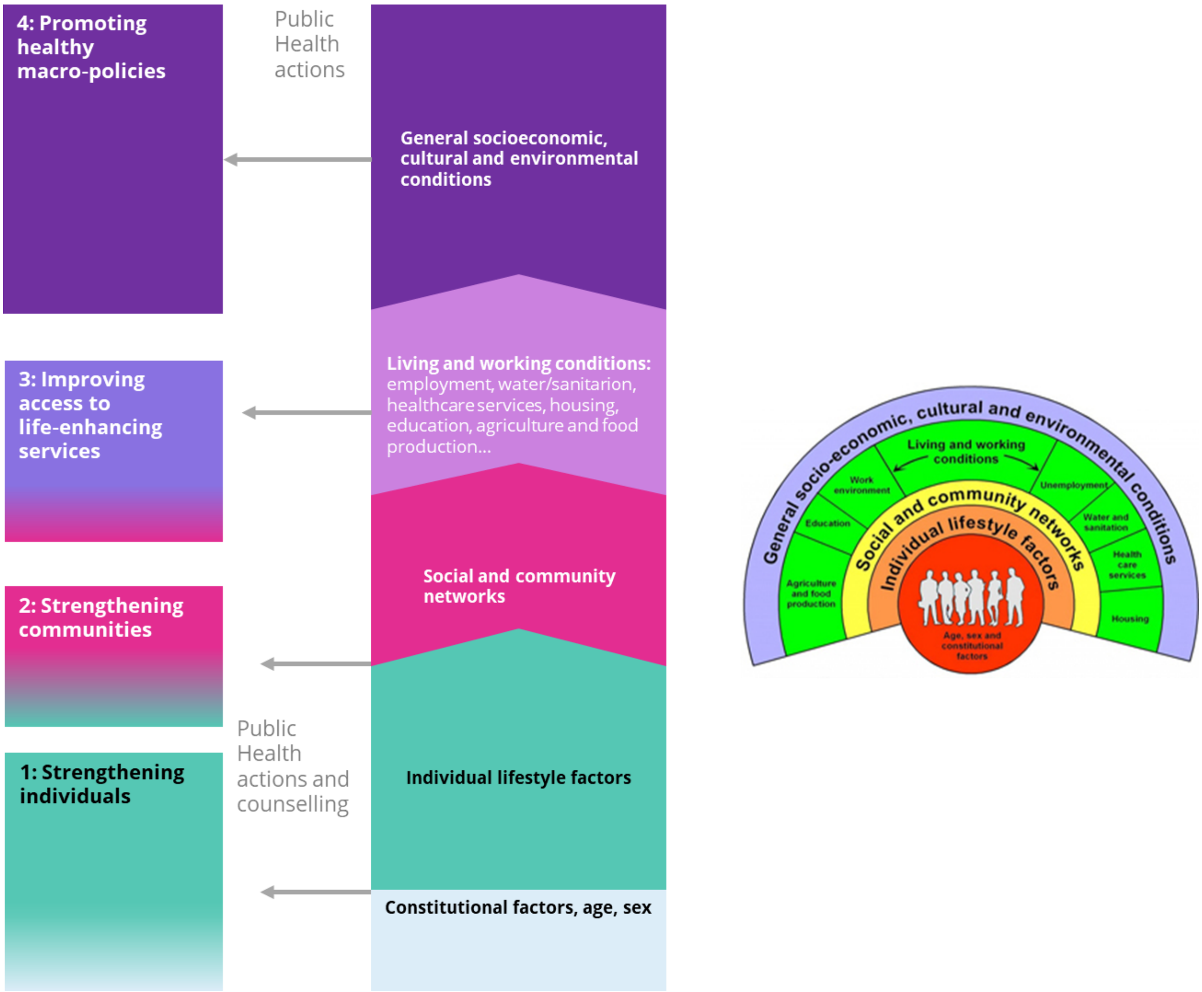

Figure 6 - The relation social determinants of health and application

Prepared by the authors. Sources (Whitehead 2007; Dahlgren and Whitehead 2007)

Thus, during this dissertation, and further described on the methodology, an adaptation of the socio-ecological models was conducted and used to analyse all factors involved in counselling, health literacy, access to information, self-management, decision-making, or community empowerment. All factors are analysed at micro, meso and macro levels (Figure 7), considering the data emerging from the research and the aforementioned socio-ecological model, adjusting mutually for offering a comprehensive and able to be translated into practical recommendations.

Micro-level factors

- Intrapersonal factors: resources (related to meso and macro-level), behaviours, attitudes, motivations, personality, diseases and any other intrapersonal characteristic, including the intrapersonal communication
- Interpersonal factors: micro-level interaction between a small number of subjects (e.g., patient-provider)

Meso-level factors

- Organisational factors: factors internal to the institutions and organisations in touch with more vulnerable communities and/or individuals (healthcare centres, day centres, social workers, etc.)
- Communities' factors: idiosincratic and specific norms, values and culture of the community; in particular, counter-hegemonic and subaltern communities, not fully aligned within the hegemonic culture and its ideology (which is considered at macro-level)

Macro-level factors: policies, systemic and structural determinants

- Includes political, economic and general social framework at a widest scale, as well as the factors able to co-determine (top-to-bottom) the communities and individuals' lifes
- The national organisation of the healthcare and socialcare systems is considered as a macro-level factor, meanwhile the local particularities could be considered as meso (organisational) or macro (policies) level depending on the overal context of the studies analysed
- The hegemonic culture and Ideology is considered as a macro-level determinant

Figure 7 - Framework for analysing micro, meso and macro-level factors

Communication and counselling

Types of communication: intra and interpersonal communication

Health communication could be referred to intrapersonal and interpersonal communication. On the one hand, **intrapersonal communication** refers to self-reflection, cognition, motivations, evaluation of choices and the reactions of others, decision-making, and the internal assumptions and dialogues that underlies our interaction with others, as well as the patterns for expressing ideas (word choices, longer or shorter phrases, etc.) and the efforts for understanding others and being understood (Berry 2007, 10–11).

On the other hand, **interpersonal communication** refers to the interaction with others, how the information is received, and the results during the communication intercourse. Intrapersonal communication is closely linked to intrapersonal communication and the evaluation and monitoring of the interaction. Some relevant examples of interpersonal communication are the communication between healthcare providers (HCPs) and patients within the medical consultation of care contexts, the 1:1 counselling, the communication patterns observed, interpersonally, between patients during health education programmes, the strategies and cues used by those programmes for increasing health literacy in order to raise health outcomes or changing the patients' behaviours or the strategies and actions for promoting public health at a larger scale. Communication is always mediated by messages previously conditioned by cultural-social backgrounds, Ideology and power imbalances.

Counselling: Health communication in the medical consultation

The communication between clinicians and patients is studied considering the interaction with HCPs, the shared decision-making mechanisms, the counselling act or the patient engagement techniques. Power imbalances always mediate Patient-Providers communication, and it is an asymmetric relationship, as has been furtherly explained in the Section on

Empowerment and, specifically, *Shared decision-making and authority: confronting paradigms.*

Firstly, enablers for enhancing the communication efficacy during the counselling process should be analysed, considering the patients' baseline conditions, the system and policies and the availability and access to health care, and the unique circumstances in which counselling can require inter-cultural – even multi-disciplinary – elements.

The patients' baseline conditions and their previous engagement in health behaviours or self-care, empowerment, self-esteem, and self-efficacy perception mediate and influence the communication intercourse within the counselling and the medical consultation. Once the patient enters the care system is increasingly important to show mutual respect, trust and facilitate the understanding and experience exchange between patients and providers, devoting enough time for discussing in primary care (Trappes-Lomax, 2016). **Patient-centred care seems to be a key for improving the communication between health professionals and people (Hesse, 2018); positive relationships and perceptions about physicians' competencies contribute to communication efficiency.**

Also, affectionate communication, explicitly and implicitly showing care, concern, kindness, positive language and emotional support, trust (believing the provider or the patient is competent, reliable) optimise the communication: empathy, interpersonal skills, and emotional intelligence has also been associated with clinical competence versus dismissing patients' contributions and showing authoritarian attitudes for reinforcing traditional roles and power asymmetry (Hesse, 2018). Open-mindedness, non-judgemental attitude, social relaxation, understandable use of language and terms, appropriate explanations, legitimising the illness experience and promoting self-care are facilitators for communication and enabling patients.

Intercultural competence is also a key enabler for interacting and empower patients, specifically, for those minorities and racialised communities; this communication competence should differentiate between its affective, cognitive, and behavioural dimensions and, so, intercultural sensitivity, awareness, and adroitness, respectively (Yilmaz 2016). The table below maps and summarises evidence revised, hypothesising which facilitators could play a major role within the clinical consultation.

Table 1 - Facilitators for communication and counselling

Micro-level: intrapersonal and interpersonal factors	
Intrinsic facilitators of patients: empowerment, self-caring skills, copying strategies, health status, flexibility and confidence in oneself	Frost, 2015; Edwards et al, 2009; Oprea, 2009; Trappes-Lomax, 2016
Competencies perceived (emotional intelligence related to communication and care)	Hesse, 2018; Frost, 2015; Oprea, 2009; Joseph-Williams 2014
To have a long-term condition	Joseph-Williams 2014
Patients' competencies and motivation for information seeking	Edwards et al, 2009
Positive relationships; affectionate behaviours	Hesse, 2018; Frost, 2015; Oprea, 2009; Joseph-Williams 2014; Trappes-Lomax, 2016
Participation in shared-decision making, agreements and conversation	Hesse, 2018; Trappes-Lomax, 2016; Frost, 2015; Oprea, 2009; Chewning, 2012
Meso-level: organizations and communities	
Continuity of care	Trappes-Lomax, 2016; Frost, 2015; Oprea, 2009; Joseph-Williams 2014
Sufficient time for consultation	Joseph-Williams 2014; Frost, 2015
Nurses as mediators	Joseph-Williams 2014; Trappes-Lomax, 2016
Intercultural competency	Yilmaz, 2016; Edwards et al, 2009
Professional culture, background and assumption of the discourse of "patients‘ choice“ and "autonomy", influential advocates	Edwards et al, 2009
Macro-level: policies and systems	
Patient-centred care	Hesse, 2018; Trappes-Lomax, 2016
Rapid access to healthcare (acute)	Trappes-Lomax, 2016

Besides, there are various patient-related barriers to clinicians-patients communication, as explained by Trappex-Lomax (2016), mostly related to traditional frameworks for interacting within a medical consultation, personality-related barriers, lack of continuity of care and social determinants of care (and so, of health) including those referring to the healthcare system limitations, time, burden and resources available. Socially assumed ‘credentialism’[4] – and credentialism as a mediator of trust - could also be a barrier for clinicians when confronting patients and trying to engage them. In other words, “Trust might be based on the clinician’s knowledge and length of training taken by the health professional“ (Joseph-Williams, Elwyn, and Edwards 2014). Varying views about patient information value, although other sources, such as the Internet, may be contradictory or unreliable (Trappes-Lomax 2016). Also, patients might believe that their right to participate in shared decision-making depends on whether they pay for their healthcare or not and passive behaviour is directly reinforced by clinicians (Joseph-Williams, Elwyn, and Edwards 2014)

Personality (empowerment as an imposition, feed abandoned by health professionals, catastrophising or low self-esteem), individual coping abilities, or feelings of fear and stigmatisation determines and undermines the counselling and diminishes the information exchange. In addition, patients are asked to be “simultaneously self-reliant and compliant”, and there is poor communication about daily management, fears, expectations and needs (Frost, Currie, and Cruickshank 2015; Joseph-Williams, Elwyn, and Edwards 2014). As previously explained, motivation plays a major role in both intrapersonal and interpersonal communication: extrinsic motivations for behavioural change act as a barrier; to feel “pressured by some interpersonal (e.g. doctor, family or others) or intra-psychic force" is, in fact, a barrier for communicating, for engaging in counselling and, to some extent, to foster a sustainable behavioural change towards healthier habits (Oprea 2009)

Also, disease-related barriers must be considered (such as lack of diagnosis, co-existing conditions, pain, fatigue, depression, inability to maintain general well-being or worsening health despite adherence). Social and material resources related barriers are the lack of personal, social or material resources, financial hardship, limited literacy, low family Support or lack of social networks, competing family and household priorities or carer responsibilities, unemployment or housing issues (Frost, Currie, and Cruickshank 2015).

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[4] Social or socio-cultural status mediated by the acquisition of credentials and qualifications within the formal education system.

HCPs' attitudes and prejudices might suppose a barrier to communication, dismissing patients' contribution or time spent looking for information, differing one from each other on defining empowerment or considering self-care as a mere "add-on" instead of a part of everyday life. Systemic barriers (silos of care, contexts, service fragmentation, pressures to reduce consultation time and frequency) also entails a substantial problem for communicating effectively and implementing shared decision-making, promoting self-care and long-term relationships. Other barriers for enablement in primary health care are to live in deprived areas, patients with poor general health, long-standing problem, emotional distress, delays in call answering or callback and shorter consultation - thus, lack of time for exchanging information and accomplishing the patients' and providers' informational demands (Frost, Currie, and Cruickshank 2015; Edwards, Davies, and Edwards 2009).

Counselling is directly linked to decision-making: assuming the role of counselling in the choice of treatments and care pathways, the communication between the patient and the HCP is crucial; counselling and access to the information, as well as the information sharing between providers and patients, also show a clear relation in regards barriers and facilitators.

Authoritarian attitudes, dismissing and dominating decision making and avoiding to listed and respect patients‘ concerns through using negative verbal and non-verbal behaviour disempower patients and reinforce unfair power imbalance: moreover, authoritarian providers undermine the information exchange and the disposal to disclose sensitive information; the authoritarian position also inhibit the proactive decision-making and to the sharing-decision making as, consequently, the communication within a medical consultation (Edwards, Davies, and Edwards 2009; Joseph-Williams, Elwyn, and Edwards 2014). Disempowerment, low literacy and low skills for searching, finding and selecting information are also some of the most significant barriers to communication in the counselling, including too poor Internet literacy, which leads to an uninformed interaction of the patient with the HCP (Joseph-Williams, Elwyn, and Edwards 2014).

Social determinants of health act, as well, as social determinants of the communication within the counselling process: ethnicity, gender, class or age (older and younger groups are susceptible to confront these barriers), system conditions and resources, traditional paradigms (authoritarian relationship, medical jargon and unclear language), lack of time, clinicians' attitudes (seemed too busy or hurried), poor continuity of care and too many clinicians involved, not being known personally by the clinical, lack of privacy, impairments, nature of the health condition (so, stigmatisation) or patients' assumptions about what is a "normal" patient (this is, a passive patient who delegate all decisions on clinicians) are barriers. Patients might fear *bad*, harmful consequences if they make a decision as well, and also consequences as regards care received by health professionals after being labelled as inflexible, troublesome or "difficult" patients (Joseph-Williams, Elwyn, and Edwards 2014). Related, and from the clinicians' side, barriers to communicating with patients may be the overspecialization, lack of reimbursement or incentives, sub-optimal information flow between health professionals, poor interpersonal skills or tackling embarrassing or sensitive topics (sexual-related side effect, end-of health, among others). Besides, trust can act as a barrier because it can lead patients to be passive in consultations, and both – patients and health professions – might fear that shared-decision-making may delay treatment (Trappes-Lomax 2016).

The social construction of race and ethnicity and ethnic stereotypes about patients' normative beliefs and practices affect the interpretation of information about symptoms. Lack of culturally-tailored care, language difficulties (fail to understand patients’ concerns, misdiagnosis, etc.), culturally formed role expectations and general conceptions of health and illness severely impairs the communication between HCPs and patients, limiting the sharing decision-making for ethnically diverse populations as well, hindering their opportunity for empowering in the medical consultation and self-managing their own health (Edwards, Davies, and Edwards 2009).

The table below maps and summarises evidence revised into barriers to communication and their role within the clinical consultation:

Table 2 - Barriers for engagement, communication and decision making

Micro-level: intrapersonal and interpersonal factors	
Patient's social and material-related barriers (Financial hardship, limited literacy, isolation, etc.)	Trappes-Lomax, 2016; Frost, 2015; Joseph-Williams et al., 2014
Disease (duration, worsening health, prognosis, lack of impact of behavioural change, etc.)	Trappes-Lomax, 2016; Frost, 2015
Patients' competencies (information seeking and selection, etc.)	Trappes-Lomax, 2016; Edwards et al, 2009

Lack of motivation (From both sides)	Trappes-Lomax, 2016; Edwards et al, 2009
Personality (passiveness, self-esteem, fatalism, dependence, etc.)	Trappes-Lomax, 2016
Coping abilities and strategies	Trappes-Lomax, 2016
The traditional power imbalance in the medical consultation, authoritarian professionals; dismissal of patients' experiences; disempowerment; medical jargon and unclear language	Trappes-Lomax, 2016; Joseph-Williams et al., 2014; Edwards et al, 2009; Hesse, 2018
Poor communication about daily strategies	Trappes-Lomax, 2016; Joseph-Williams et al., 2014
Communication reduced to biological issues and outcomes	Trappes-Lomax, 2016; Joseph-Williams et al., 2014
Meso-level: organizations and communities	
Cultural barriers; lack of cultural tailored care	Edwards et al, 2009
Macro-level: policies and systems	
Organisational barriers (service fragmentation, over-specialisation, internal communication issues, lack of continuity, pressures to reduce consultation time, etc.)	Trappes-Lomax, 2016; Frost, 2015; Joseph-Williams et al., 2014; Trappes-Lomax 2016
Stigmatisation	Trappes-Lomax, 2016; Edwards et al, 2009

Information and health literacy

Formal, non-formal and informal education

The acquisition of information – in particular, the rapidly changing and highly specialised information about health and disease – is a very complex process; information may be acquired by observation of others and, in particular peers, by the socialisation processes, by the interaction and feedback from professionals, by informative sources such as traditional mass media (e.g., TV or newspapers), the Internet, magazines even journals, courses and through the educative system, among others. The competency for acquiring information is highly determined by social conditions, being the social class and the previous education the most important ones, as explained before in the Theoretical Foundation (Béduwé and Planas 2003; Planas Coll and Casal Bataller 2003; Galobardes 2006).

Before introducing the question about information access and health literacy and education, it is relevant to define formal, non-formal and informal education, also referred to as formal, non-formal and informal learning. All these three types play a significant role and have a massive impact on the abilities and competencies of the individuals for accessing, filtering, selecting, and analysing the information, and are present, to some extent, during the whole life of all persons, impacting on the subsequent results and outcomes.

Formal education refers to the education acquired within the Education System; thus, regulated education. It is mediated by schools, high-schools, VET (Vocational Education and Training) centres or Universities, among others (Tudor 2013; Läänemets et al. 2018). The description acronym VET also deserves some consideration as long as the nature of the regulated VET is aimed at merging education – which may entail some purely cognitive, academic, theoretical, about learning and contents – and training- which usually implies some practical, applicable and/or real-life learning(Vallina Acha 2015).

Non-formal education refers to the education acquired in non-regulated education programmes (Tudor 2013; Läänemets et al. 2018). For example, long-life learning courses, on-the-job training courses and programmes and, to some extent, the CDSMP (Chronic Disease Self-Management Programme) or EPP (Expert Patients Programme) for health literacy, specifically in chronic diseases, among others. These programmes are structured, normalised and implemented in a certain way following a defined methodology.

Informal education (or informal learning) is the act of learning through the experience (OCDE n.d.; Tudor 2013). It can be a self-directed act (e.g., to self-direct and self-manage unstructured research about one's disease through several sources, even to consult to several professionals and expert) or non-structured learning through peers and, most important, relatives and the immediate social network (e.g., to see, in family, documentary films about one's health condition, to go to the Museum, or the selection of books and resources available at home). Informal education is very relevant learning for all individuals and has a significant impact during the whole life: it is determined, to a greater extent, by the socio-economic and socio-cultural position of the family and the peers/social networks, by the social integration of the family and its position within the societal field, and directly resonate in the formal education outcomes and results and, then, in the non-formal education opportunities (Béduwé and Planas 2003; Planas Coll and Casal Bataller 2003; Galobardes 2006; Bourdieu and Passeron 2008; Stinchcombe 1972).

Access to information, self-directed and informal education

Health literacy "represents the cognitive and social skills that determine individuals' motivation and ability to gain access to understand and use information in ways that promote and maintain good health"[5]. Health literacy can be acquired through the informal education (self-directed health literacy) and entails an autonomous access, selection and evaluation of the information sources used for increasing the individuals' knowledge, skills, and decision-making capabilities.

Higher levels of literacy, education and self-efficacy and appropriate access to the information facilitate the access to self-directed health education, also supported, at the interpersonal level, by peers (friends, family), patients' advocates, experts, and healthcare professionals. Integrated and easy-to-navigate healthcare systems facilitate the acquisition of health education and improve individuals' access to reliable information; these systems should interact coherently and consistently with cultures and customs, stakeholders, and communities reached. **Socio-cultural**

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[5] as defined by Nutbeam (Edwards, Davies, and Edwards 2009)

inequalities and economic disparities suppose a major barrier for health literacy and self-directed education.

Determinants of health literacy, apart from the class as mentioned earlier, economic, and socio-cultural determinants, are the motivation for actively seeking information, competency in information seeking and analysis, experiences of poor information exchange in prior consultations, and, in some case, the prospect of anonymity. Health practitioners-dependent facilitators for fostering patients' health literacy - and thus, shared decision-making which is closely related - are the assumption of the discourse of "patients' choice" and "autonomy", influential advocates (health consumer groups, women's movements, or policy makers, among others), medical education, professional culture and cultural background (Edwards 2009). Open-minded health professionals who show social relaxation and sustain non-judgmental attitudes enable patient's autonomy and, consequently, the acquisition of health literacy (Yilmaz, 2016).

* * *

Poor search skills and limited awareness of the origin of information sources, and poor health literacy is associated with decreased ability to participate in shared decision-making: it conditions a powerless or disempowered person, passive recipients of the information who do not desire responsibility for informing themselves and make decisions over their own health (Joseph-Williams, Elwyn, and Edwards 2014). Despite the negative perception of some providers towards autonomous informal health education and health literacy, health literacy and Internet-related skills – sufficient for searching, assessing, and analysing information – are at a lower risk of misinformation, less exposed to fake news and more prone and equipped for informed choice. As Edwards et al. explain:

> "[the] more Internet or health literacy skills patients have, the more likely they can manage the risk of misinformation. Individuals who have skills in health literacy and are able to use information effectively are potentially empowered in health-care consultations".

Health literacy Programmes and non-formal education for the acquisition of health literacy

Although Health Education within the formal education system is an increasingly demanded even implemented subject or transversal content in some countries (Auld et al. 2020; Çalik and Çan 2012), most health education is obtained through informal health literacy and self-directed learning non-formal education programmes. Non-formal health education refers to all those initiatives and programmes carried out to increase health literacy, assuming that more literacy is directly correlated with positive behavioural change and, so, better health outcomes through self-management. Research focuses on several programmes, being the most studied the CDSMP and its different adaptations (e.g., DSMP for T2D), the Expert Patient Programme (Tomioka et al. 2012; Greener 2008; Ahn et al. 2015; Grintzali et al. 2017; Wilson 2008; Corvin et al. 2017; Detaille et al. 2010; Hevey et al. 2020), both group-based programmes, structured and following a predefined methodology, or Patient Navigator model (Doolan-Noble et al. 2013; Carter et al. 2018). The political context within which this policy has occurred should also be envisaged: the population has been increasingly urged to take care of their health, leading a healthier lifestyle. Moreover, the still-poor information quality within the healthcare system could be one reason for engaging patients in self-care (Greener, 2008). A chronic disease diagnosis often entailed a loss of meaning, purpose and hope: peer-based interventions may help deal with the isolation, the sense of loss, the renegotiation of the self and the difficulties in the socialisation that may arise (Embuldeniya et al. 2013).

Research also showed major challenges regarding the sustainability and implications of non-formal patients' education programmes, specifically the most structured ones. Firstly, the programme's cost-effectiveness is far from being clear and the literature shows contradictory information (Greener 2008; Dale, Williams, and Bowyer 2012; Hevey et al. 2020), while recent research showed an important reduction in GP visits (Hevey et al. 2020)[6]. Besides, while the CDSMP and EPP are presumed to be peer-based patient education, these are not able to overcome the power imbalance; moreover, it seems that they are adapted to the power hierarchy

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[6] Please, note that the CDSMP is a copyrighted and commercialised programme, thus the literature authored by its creators about the cost-effectiveness of the programme is not analysed.

and its reproduction within the system (Amann, Zanini, and Rubinelli 2016; MacLellan et al. 2015). Secondly, the time required and administrative task are challenging for peer supporters or trainers and managing the relationships with the peers trained (blurred lines, acceptance, role confusion, pressure to be a role model, inhibition, etc.). The relationship with health professionals involved is complex and challenging for trainers. The power imbalance and disempowerment observed in the medical consultation is reproduced in the vast majority of peer-based interventions; likewise, health professionals might be reluctant to peer education, peer support and similar initiatives in both settings, offline and online (MacLellan et al. 2015; Embuldeniya et al. 2013; Amann, Zanini, and Rubinelli 2016). The following table summarises the key challenges and issues arising in the non-formal education programme through extracts and quotations:

Table 3 - Extracts summarising key challenges in non-formal health education programmes

(Greener 2008)	*"individuals felt they were embarking upon 'unfamiliar trajectories' because of the permanent nature of long-term conditions, and the lifestyle change often associated with their contraction.* *patient expertise lies in their 'views and situation' rather than in medical expertise, which will only apply to a 'minority of patients'* *The national evaluation of the Expert Patient Pilot programme found very little in terms of cost-saving as a result of the programme.* *'moderate' gains in self-efficacy and small gains in energy, but no impacts on routine health service use* *increases in out-of-pocket costs coming from an increased use of alternative therapies and home helps.* *does not mean a loss of power for clinicians; debates are couched entirely in their terms.* *the 'expert' part of Expert Patients is framed within a specific system of thought that is biomedical*
(MacLellan et al. 2015)	*peer supporters could emotional[ly] disconnect* *lost opportunity if they were unable to connect with a patient* *lack of motivation to continue in the role* *time commitment* *Patients were unaware of the role of the peer supporters* *Challenging transition from the role of service user to peer supporters challenging, to draw the line between service provider and friend* *pressure to gain acceptance from the team* *multiple, shifting identities of the peer supporters* *The 'lay expert' position sometimes caused role confusion* *peer supporters exposed to criticism by others* *peer supporters work was described as relational and not captured in service documentation* *manage time for the administrative commitment* *too much responsibility*

	too much pressure to be a role model
(Embuldeniya et al. 2013)	*the expert self- managers produced by peer support programs were shaped within both empowerment and medical paradigms* *the content and structure of interventions often reinforced traditional biomedical power.*
(Dale, Williams, and Bowyer 2012)	*lack of data related to cost-effectiveness* *little research aimed at understanding the clinical and psychosocial benefits gained as a result*
(Amann, Zanini, and Rubinelli 2016)	*HPs perceive the increasing trend of online health information as a threat to their control and medical authority, some even adopt strategies to discourage or undermine patients' online information seeking efforts.*

Regarding health outcomes, and similarly to cost-effectiveness, evidence is weak and limited (Dale, Williams, and Bowyer 2012; N. Wright et al. 2011): further evidence is needed to design and implement well-founded interventions as well as for providing advice on good practices. Sometimes, studies are biased since their design and, sometimes, designed for showing positive outcomes; RTCs report less evidence of beneficial impact and, as no pattern emerged and there is a lack of evidence, at this stage, we would not suppose the superiority of any model of peer support - e.g., CDSMP or the EPP (Dale, Williams, and Bowyer 2012). However, continuity of care is important as well as to suit the interventions to each group, including the overall and previously assessed health literacy level; interventions should be culturally-tailored and considering the unavoidable power imbalance and the new power relationships formed during the peer education initiative (Dale, Williams, and Bowyer 2012; N. Wright et al. 2011; Embuldeniya et al. 2013).

On the one hand, Deficits in health literacy, concerns as regards confidentiality in meetings, and medical authority suppose barriers (Embuldeniya et al. 2013); as regards the last factor, lack of support from health professionals, threatening or symbolic fight for the role undermines the sustainability of the initiative. Sometimes, the conflict between PSW and HPs leads to contradictory advice and, then, conflicts and confusion for patients (Embuldeniya et al. 2013; MacLellan et al. 2015). Social background, culture, even gender, ethnicity and age are relevant for forming sustainable groups to some extent while challenging experience of illness or marginalisation results as a barrier (MacLellan et al. 2015; Dale, Williams, and Bowyer 2012). However, in the specific case of HIV in prison settings, a non-positive trainer seems to have better prevention outcomes (N. Wright et al. 2011). Mutual support and reciprocity, taking back blurred lines in peer-supported groups, could be a source of misunderstanding and internal conflict(Embuldeniya et al. 2013). In an online community, the lack of involvement and activity, social ties and activity of all members undermines the sustainability and the health outcomes of all people involved (Amann, Zanini, and Rubinelli 2016). Both settings of mutual support must consider the selection biases when evaluating the results: this selection bias cannot be avoided as long as the participation is voluntarily accepted but those chosen to take part are more favourably disposed, motivated, and more likely to gain benefit from the intervention (Dale, Williams, and Bowyer 2012).

On the other hand, the flexibility and adaptation to local needs – including, e.g., development and validation for low literacy, clinical-related, Quality of Life (QoL) related or cost outcomes and longer post-intervention assessment – facilitate the engagement in patient education initiatives (Clement, 2019). Personal relations also play a significant role: experiential knowledge of mentors or training and exchange of experiences improves the engagement and are an essential resource for training peers and change their outlook by social comparison and providing a new perspective on one's situation for setting goals and coping with the illness from a new perspective (Embuldeniya, Gayathri et al., 2013).

Target population, educational backgrounds, behavioural approach, recruitment methods, information received and gave during seminars, adequateness of expectation, location, frequency, duration, and flexibility may contribute to the take-up and effectiveness of peer support. It must be considered during the design (J. R. Dale et al., 2012).

Thanks to its reciprocal nature, mutual support, and shared illness experiences suppose an attractive feature of peer-to-peer patients' education. Participants highly value connection with peers: it provides them with the safeness and integration of their physical condition into their lives, embodying social participation (MacLellan, J. et al., 2015). Goal settings, self-disclosure and a positive environment for raising responsibility and commitment are usually mentioned as key to peer education.

The sense of connection, mutual feelings of rapport, shared disease – instead of various diseases in the same seminar -, shared challenges, similar experiences, personal and social characteristics and similar lifestyle, culture, values and beliefs are facilitators for engaging people with chronic diseases and, especially, those more socially vulnerable. Peer education provides a genuine relationship between equals with a little power imbalance and role models within the community (peers). Mentors have "authority, credibility, and more insight into their feelings and daily experiences than professionals“ and "personal understanding of how difficult it is to change behaviour". Peer education allows them to meet and share with similar others in a safe and non-threatening space. However, mentoring might be an overwhelming task: it is required adequate support for mentors and connecting mentees with other supportive networks before intervention (Embuldeniya, Gayathri et al., 2013).

In sum meaning, the flexibility of the training role, and how encounters are managed are considered critical factors for a peer-led programme's success. Education programmes and interventions should be culturally-tailored and plenty adapted to its end-users group: intervention design cannot ignore the fact that groups should not be formed by very heterogeneous populations, as it might reproduce the social asymmetry and inequality, perhaps discouraging some participants or groups of participants from taking an active role - notably, those more socially vulnerable, even excluded. It seems to be interesting to cluster these groups, e.g., according to the previously observed and reported in the literature health disparities, and attend their social determinants and causes.

While interventions with hard-to-reach groups must be brief and straightforward to administer, hard-to-reach populations are easily engaged through peers. For instance, Wright (2011) research on peer education in prison setting shows how ex-prisoners (rather than current) conduct better the programme than other alternatives; current prisoners mentoring a programme could project an undesired image of vulnerability to other prisoners. HIV-negative ex-prisoner led to increased condom use: in this case, the need for a similar condition and shared illnesses has not been demonstrated.

Peer support and peer-education also benefit mentors or trainers. These could better engage patients (mentees) by understanding the challenges and daily situations; fluidity enables them to move successfully between patients and health professionals, mediating relationships, and potentially improving mentees' health outcomes. The *belongingness* act as a potent motivator: *belongingness* gives them a sense of meaning, identity and self-understanding and, then, regaining control over their own lives and empowering them. Besides, mentors reduce their feelings of isolation and stimulate their self-healing abilities by help others and self-disclosure framed within equalitarian relationships (MacLellan, J. et al., 2015).

Win-win situations favour peer education if the programme allows balancing well 'control' and 'autonomy' of all participants and mentors, and mentees can establish a relation and mutual partnership based on trust.

If these interventions are online-based, genuine user involvement and active participation increase the engagement. Online interventions and online communities of healthcare users could be more engaged if they provide an attractive and usable platform, joining together heterogeneous users, a variety of roles, collaboration, and competition to foster patients' empowerment. These should be designed aimed at motivating users and their willingness to share utilizing interaction and involvement (Amann, J. et al .- 2016).

Engagement and its role for communities and individuals

Engagement is a term widely used in the literature; it refers to the community and aims at reaching a long-term alliance and loyalty with a certain audience (Holt and Chambers 2017). Engagement is not restricted to the interaction, the treatment compliance, the medication adherence, and the involvement during a predefined period, while these could be considered as dimensions or outputs: engagement means a medium and long-term sustainable relationship with feasible changes at the behavioural level, specifically, in self-caring and self-management of health. In addition, it contributes to the maintenance of health promotion initiatives but being the sustainability is a highly desired outcome of health promotion programs, yet it often eludes program planners looking to achieve it (Hanson, Salmoni, and Volpe 2009). The **community-centric approach** is an integrative process to overcome the traditional research and biomedical models limitations - such as the immutability of individual risk factors or the restrictive focus – by considering the bio-psycho-social perspective (O'Campo and Dunn 2012). **Community-centric approaches** can unveil factors that may condition the acceptance of public health campaigns or behavioural change. Consequently, engagement and empowerment are central concepts.

Engagement usually refers to the community to reach a long-term alliance(Holt and Chambers 2017). The engagement is related to health outcomes for communities and individuals. It is suggested that involving patients as partners in the long-term facilitates patient-centred care delivery (Lawrence and Kinn 2012), ensuring that research efforts address relevant clinical questions through the co-design of the agenda, leading to a more appropriate and robust research design, which may imply to involve community stakeholders (Brett et al. 2014). The engagement ought to be related to health outcomes for communities and individuals: it is suggested that involving patients as partners at long-term and community stakeholders facilitates patient-centred care delivery (Lawrence and Kinn 2012). In addition, community could maximise the real-world applicability of interventions in community healthcare practice (Bodison et al. 2015), fostering the engagement and the research efforts to address relevant clinical questions and lead to an adequate research design (Brett et al. 2014).

Individuals’ engagement

At the **individual level, <u>individuals’ engagement</u>** infers the involvement and active participation of persons in the therapeutical or research process integrating information, professional advice, personal needs and preferences, and their own competencies to manage health (Flournoy 2011). It may also involve a medium and long-term sustainable relationship with feasible changes at the behavioural level, specifically, in self-caring and self-management of health. Moreover, it contributes to maintaining health promotion initiatives by fostering its sustainability over time (Hanson, Salmoni, and Volpe 2009). Patients’ knowledge, health conditions, beliefs and experience impact their decisions to be engaged in policy-making, innovation, interventions and initiatives and, probably, in research projects (Vaismoradi, Jordan, and Kangasniemi 2015).

Engagement necessarily infers that a patient is involved in the process, then patients “harmonize vital information with professional advice, personal needs, preferences, and abilities to manage their health influenced by their own personal characteristics, disease and characteristics of the setting at organisational, community and policy levels (Flournoy 2011).

Facilitators of individuals’ engagement are the baseline conditions (previous knowledge, health conditions, beliefs, previous experiences), the HCPs attitudes, encouragement and support (Vaismoradi, Jordan, and Kangasniemi 2015), a balance between control & autonomy, mutual trust and involvement in decision-making (Amann, Zanini, and Rubinelli 2016). Participatory approaches and reduced power imbalances – or, if it is not possible, a real awareness of power differentials – act as enablers of individuals’ engagement in healthcare, leading to the aforementioned outcomes. On the contrary, patients with low-self-efficacy tend to cede all the control to the HCP, lacking communication and social skills, experiencing lower levels of support and a poor involvement as ‘active’ patient; also, problems regarding resources and infrastructure and providers’ communication skills and style should be revised (Vaismoradi, Jordan, and Kangasniemi 2015). The patients’ involvement restricted to mere observation/reading, and providers’ authoritarian styles of communication may diminish the engagement in healthcare (Amann, Zanini, and Rubinelli 2016), also impacting on decision-making and self-management.

Community engagement

Community engagement (CE) includes patients and service users participating in healthcare innovation, development of services, policy agendas or research. It entails a long-term involvement (co-production) and alliance at the community level as a whole, implying a multistakeholder approach (Tiwari, Stephens, and Hooper 2019; Ivory, O'Donnell, and McFarlane 2019; Rendalls et al. 2019).

The CE includes a broad range of parties (stakeholders): community leaders, advocates, community health workers, health professionals, public administration officers and service users (patients). Moreover, these groups should be carefully defined before designing the strategy for recruiting, disseminating, and communicating health interventions and research results. Activities for sustaining the CE should be demarcated too, and these should include plans far beyond the mere passive receptiveness of information.

Reports on CE show greater emphasis on the engagement with patients and health professionals than in the engagement with stakeholders and key decision-making players: these are more frequently involved in the research's design phases (Concannon et al. 2014). However, research shown that collaborative efforts during the whole research lifecycle improve the quality of outcomes: the involvement of patients in the healthcare innovation process is increasingly recognized as the main asset to favour.

The individuals' engagement has major relevance in CE, as well as the mutual trust at the community level, external linkages or institutional processes, able to show the value of the CE (Bodison et al. 2015; Brett et al. 2014) as well as the background and conditions of the community members; supportive healthcare professionals or research teams, considering the community engagement and empowerment as a goal and focused on the specific needs (Shea et al. 2017) are required for fostering the CE in several settings, including healthcare innovations, interventions, programmes, policy-making or research. Major barriers are resources available - e.g., lack of training or weak financial sustainability, time, and costs - and power struggles (Bodison et al. 2015; Brett et al. 2014); it should also be considered that hard-to-reach groups might be previously disempowered and has a perceived or actual powerlessness (Brett et al. 2014).

In sum, on the one hand, at the community level, supportive research teams and health professionals should envisage community empowerment as a goal when trying to engage the underserved populations. A culturally competent framework and more training on dissemination and implementation are required for facing challenges regarding the negotiation process when designing and conducting the research. On the other hand, disempowerment works as a key barrier at the community level: thus, ***engagement*** **precedes** ***empowerment*****, which should be, ideally, an ultimate aim or goal, a regulatory ideal.** Due to their social conditions and the traditional approach of research and healthcare, disempowered communities and individuals could be reluctant to be involved. Health professionals should encourage knowledge sharing and joint decision-making in order to drive a cultural change that leads to involve in the research hard-to-reach individuals in active roles.

The ladders of citizens' participation are very relevant here in particular when designing healthcare innovations, interventions, programmes and policies (Arnstein 1969); the following table summarises the process:

Table 4 - Ladder of Citizens' Participation. Adapted (Miller 2018; organizingengagement.org 2019; Arnstein 1969)

Ladder or stage	Description
Manipulation	Illusory form of participation signifying "the distortion of participation into a public relations vehicle by powerholders."
Therapy	Pseudo-participatory programs attempt to deviate the responsibility from governance and public administration officers and managers with real decision-making power to citizens.
Informing	Mere informative unilateral and one-way act about rights, options and responsibilities, usually paired with technical/legal/regulatory terms and jargon
Consultation	To invite to share opinions and views while sharing information.
Placation	To offer a limited degree of influence in decision-making but from a tokenistic point of view.
Partnership	Public institutions, officers, and/or managements allow citizens and communities to negotiate, veto decisions, share funding, and some sort of power redistribution.
Delegated Power	Public institutions, officers and/or managements delegate some degree of funds, control, management and decision-making to citizens
Citizen Control	Citizens are able to govern a programme or institution being in-charge of decision and policy-making

CE includes patients and service users participating in research and Community healthcare innovation while it is not restricted to involvement. Patients' knowledge, health conditions, beliefs and experience impact on their decisions to engage in interventions and initiatives and, probably, in research projects (Vaismoradi, Jordan, and Kangasniemi 2015).

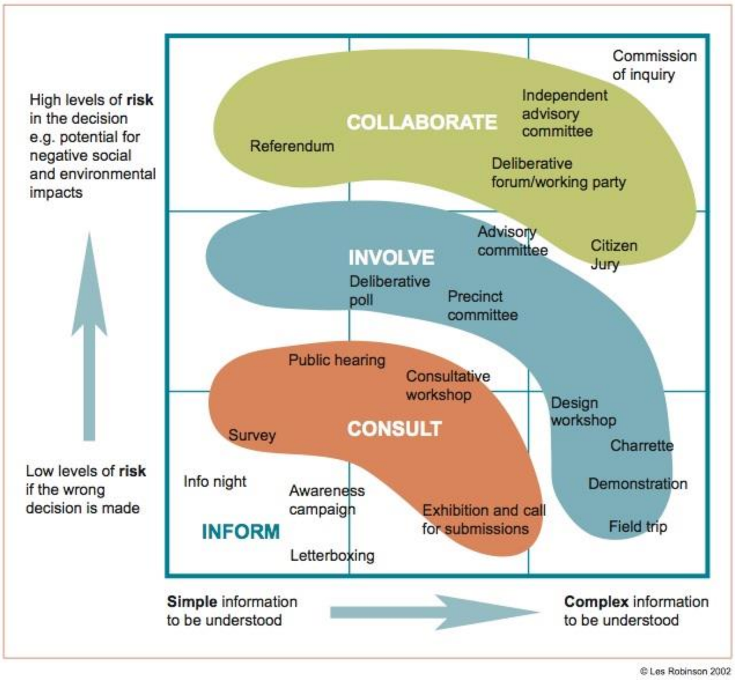

Figure 8 - Levels of Citizens' participation (Changeology n.d.)

In regards research and healthcare innovation, communities' and patients' co-production of innovations, services and policies could go from partnerships to communities' control depending on each case; even in research and co-production of programmes, some methodologies are already raising their popularity and use, such as the Community-Based Participatory Research (CBPR). The CBPR has shown its effectiveness: (i) in increasing the participation of minority subjects in research; (ii) in diminishing health disparities, determined by the involvement and the degree of engagement by communities; and (iii) for validating effective interventions among under-represented populations (Nueces et al. 2012).

Health literacy, cultural background and power balance must be well-founded on a participatory approach for engaging vulnerable persons. The attention, commitment and engagement of researchers and health professionals too is essential. The power relationships in a medical consultation will be further explored in the section on Empowerment and during the entire meta-synthesis, it will be a key theme to be researched.

A systematic review (Brett et al. 2014) exploring the impact of patient and public involvement (PPI) shown how CE research help to identify user and community relevant topics and to prioritise them for the research agenda, including the lines of inquiry, research questions and the wording of questions itself. CE also offers pragmatic criticism on the research and the dissemination of its results, helping to suit academic language to lay language – and it includes the informed consent form. However, PPI impacted the study design's robustness – because incorporating users perspectives could imply a divergence from the scientific method - and leads to power struggles between researchers and users. Results might not be perceived as necessary by the academic parties, and there are concerns about the premature disclosure of results before its publication in a Journal.

Another systematic review (Cyril et al. 2015) states that while CE is usually held as a paradigm in health promotion, components of these models and their impact on target populations' health outcomes are poorly understood. Genuine power-sharing, collaboration in partnerships, bidirectional learning, inclusion within the research protocol and intercultural competency seem to affect health outcomes, especially for underserved populations. Thus, intercultural competence seems to be a key skill for both: health professionals and researchers.

Taking up the discussion point about culturally tailored interventions and intercultural competence, it must be emphasised that health professionals and researchers must also gain a comprehensive understanding of the perspectives, traditions, values, practices, and family systems of culturally diverse individuals, families, communities, and populations they research. Intercultural competencies include the affective, cognitive and behavioural aspect, so, is formed by the intercultural sensitivity, awareness and adroitness (Yilmaz et al. 2017; Shea et al. 2017), as well as the awareness of power differentials and Ideological and social constructions behind health disparities and different levels of engagement and participation in the communities involved.

Recruitment and Engagement: hard-to-reach and hidden populations

Before addressing the **recruitment** question, it should be considered that this research explicitly differentiates between hard-to-reach, hidden and disengaged populations. **Hard-to-reach** groups are difficult to be involved in due to their physical, geographical, socioeconomic, or socio-cultural situation. **Hidden populations** are persons who do not wish to be found (e.g., irregular migrants or drug users (Shaghaghi and Aziz Sheikh 2011). In contrast, the **disengaged** may be persons or communities not actively involved or being considered in the research, co-design or even health education programmes (their degree of reluctance may vary and refers only to a lack of participation). This subdivision led to select different sampling and recruitment techniques: recruitment is a critical step in engaging highly vulnerable communities or persons in health literacy programmes, health research, even in regular healthcare, ensuring an ethically-tailored, culturally appropriate and well-focused process.

Culturally relevant recruitment techniques and a careful assessment of ethical and personal safety procedures for participants in the programme are critical: the recruitment of participants conducted by community members and leaders increases the recruitment rates and the retainment during the participatory research process (Nueces et al. 2012). Research shows that the motivation and disposition of community members to take part and engage in participatory processes are personal and professional growth, recognition and respect, sense of ownership and sense of confidence, development of leadership skills, knowledge acquisition, concurrence with prevalent cultural-norms, appropriateness of the participatory process with local environment and needs, and perceived or experienced beneficial outcomes [51]. The following table summarises the most used **techniques for sampling and recruiting hard-to-reach groups**:

Table 5 - Sampling and recruitment approach. Source: **Shaghaghi et al (2011)**

Approach	Rationale
Snowball sampling	- a non-probability method based on chain referral - rare sample characteristics - heterogeneous or broad populations
Respondent-driven Sampling (RDS)	- overcomes the selection biases observed in snowball (cooperative and motivated subjects) - chain-referral plus incentives (payment for participation, for recruiting peers…), limited recruits per participant, ensuring confidentiality (the participants can decide not to disclose their identities to the researchers)
Indigenous field worker sampling (IFWS)	- Allows obtaining privileged access to the population studied. - Informal investigators selected within the community receive training for fieldwork, methodology, interview skills, etc.
Facility-based sampling (FBS)	- recruitment methods focused on facilities frequently visited by the targeted population (e.g., bars, treatment centres, clinics…)
Targeted sampling (TS)	- allows to include previously defined subgroups of the targeted population, overweighting more readily accessible and willing to participate (Trochim 2020)
Time-location (space) sampling (TLS)	- To map, sample and recruit at specific venues or locations frequented by the targeted populations, usually at a determined time frame.
Conventional cluster sampling (CCS)	- Randomly selected clusters after data gathering - Predefined places and locations (e.g., drug treatment centres)
Capture re-captures sampling method (CR)	- Only for stable populations - Allows to estimate the size if it is unknown for the targeted sample ('Capture-Recapture Sampling' 2008)

In addition, recruitment and retention of vulnerable groups involves a significant effort in balancing the study integrity and scientific rigour and protect the participants from physical or emotional distress by planning and anticipating potential issues and risks, fostering the support systems (including among providers), and continuous monitoring of the engagement also evaluating the research environment and its safety and caring features for all participants (Gemmill et al. 2012). Research shows the necessity for complementing and merging with offline methods (Bajardi et al. 2014). Lastly, the literature showed that the motivation and disposition of community members to take part and engage in participatory processes are personal growth, recognition and respect, sense of ownership and sense of confidence, development of leadership skills, knowledge acquisition, concurrence with prevalent cultural-norms, appropriateness of the participatory process with local environment and needs, and perceived or experienced beneficial outcomes (George et al. 2015).

Adherence, compliance and self-management

Firstly, compliance, adherence and self-management of chronic conditions should be defined.

On the one hand, compliance and adherence refer directly to the patients' willingness and readiness to follow the treatment instructions and, if any, reach and accomplish the treatment goals. **Compliance** seems to refer to a more passive component, while **adherence** requires the patients' active engagement and their proactiveness during the whole process (Lutfey and Wishner 1999).

On the other hand, **self-management** of a chronic condition – or several – involves an adherence to the treatment and also putting in place all those measures and behaviour changes needed for optimising the health outcomes and for implementing a self-care routine, including the acquisition of healthier habits for mitigating the illness' impact and the assumption of the need of a behavioural change from an active and accountable view (Grady and Gough 2014; Anekwe and Rahkovsky 2018). Self-management may involve, as well, the acquisition of information and informal education about one's disease in order to nurture and enhance the knowledge base needed for conducting an effective self-care routine, pathways and informed decision-making.

Autonomy and self-efficacy, decision-making and self-management

Sense of agency refers to the fact of being a moral agent, interacting with others in a complex societal network, feeling competency and control over actions and their consequences (J. Moore 2015). Due to the 'polysemy' of the expression and its different use and meaning in Philosophy and Psychology, which entails a risks of further stigmatisation of already stigmatised and vulnerable populations, **in this dissertation '*sense of agency*' is substituted the conjunction of autonomy and self-efficacy**, trying, at the same time, to characterise the so-called 'individual empowerment'; however, individuals' empowerment is not used, in general, during the whole dissertation because of its intrinsically links to collectively, communities, actions and societal, policy and political changes, further examined in section Empowerment: empowered persons, empowered communities and, also, in Chapter 5 on Synthesis and discussion.

The conjunction of the individuals’ autonomy and self-efficacy, decision-making, and self-management of health should be clarified before addressing its challenges and factors in the Chapter 3 on Analysis Results and unveiling the potential mechanisms that may underlie the complexity of the relations between these three factors.

On the one hand, decision-making, the act of choosing pathways of treatment, self-care, and the absence of treatment are related to the patients’ participation and influence the patients‘ engagement (Chewning, 2012). To have a long-term condition, attitudinal change and clinicians‘ communication skills facilitate shared decision-making (Joseph-Williams 2014); however, shared decision-making requires adequate time for discussion, continuity of care and relationship building.

Considering the engagement of patients, relevant factors are the role of nurses as mediators, patients‘ confidence (feeling that it is acceptable to raise a question) and a more active attitude from patients (e.g., if they recognize the contribution and importance of their personal preferences and experiences), sense of partnership, positive past experiences with the clinician, good reputation and clear explanations about options towards with earlier provision of information and an individualised approach. Continuity of good relationships, trust, flexible and individualised support, and valuing patients' own experience are also highlighted as facilitators for engagement in self-care by Trappes-Lomax (2016). Clinicians could facilitate shared decision-making and the relationship in general terms, avoiding dominating the consultation who do not dominate the consultation, listening and respecting patients‘ concerns, understanding individual needs and preferences and providing sufficient information in non-medical and layman terms (Edwards, Davies, and Edwards 2009; Joseph-Williams, Elwyn, and Edwards 2014).

Decision-making is directly linked to patients’ autonomy and self-efficacy; health literacy also plays a role in this network of goal setting and pathways selection. The link between health literacy and decision-making is clearly demonstrated by the research, as well as the studies revised in the present dissertation**: precisely the link between these dimensions is the critical point for establishing a relationship between health literacy and responsibility as a dimension of one’s agency**: health literacy covers the knowledge of health but also the healthcare system, the ability for processing and using the information and the applied competency for self-managing health and be proactive in decision-making (Liu et al. 2020).

Nutbeam integrates knowledge, skills and self-management of health within the definition of health literacy as cited by Edwards (2009); it also distinguishes between three levels: functional, interactive and critical health literacy, as detaied in Figure 9.

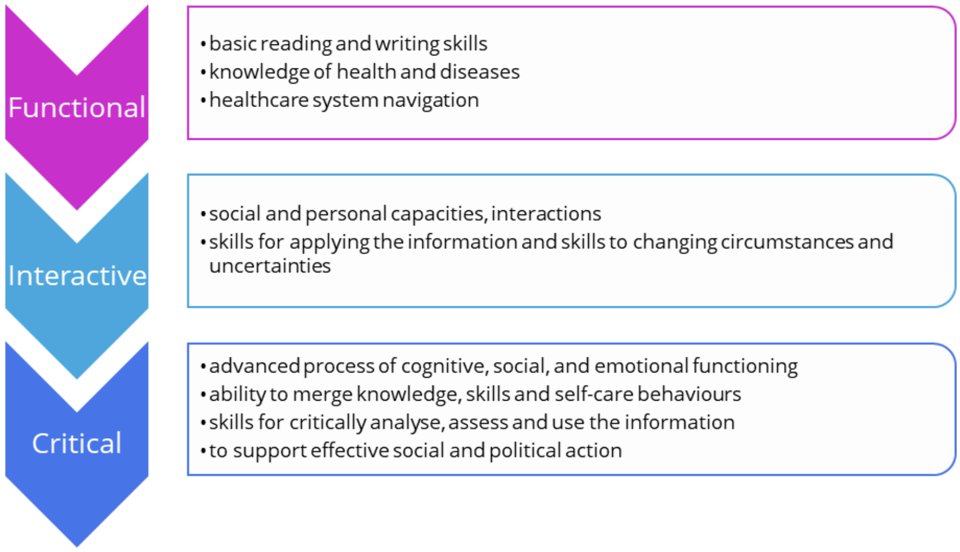

Figure 9 - Health literacy: funcitonal, interactive and critical health literacy

Shared decision-making and authority: confronting paradigms

As previously introduced in the Section on Counselling: Health communication in the medical consultation, counselling and patient-provider communication has a determinant relation to the patient’s willingness, readiness even margin of action for decision-making. It seems that consultations *dominated* by patients, supporting decision-making and respecting patients‘ autonomy shown better outcomes in terms of communication during the counselling (Frost, 2015). Relationship-centred care provides emotional support and permits the accommodation of different degrees of patients‘ autonomy.

The considerations around patients’ experiences concerning power, roles and communication in the medical consultation have changed since the 80s decade to current times; the traditional sovereign power of health professionals in the past has given way to a new paradigm based on shared decision-making, new resources, growing visibility of subaltern and counter-hegemonic groups joining collective identities behind (as a consequence) of diagnosis.

A positive view, from the HCPs, about the patients’ involvement and self-management of health and the shared decision-making fosters self-efficacy and autonomy of these patients. The patients’ engagement in decision-making seems to be ethically appropriate, promotes veracity, patients’ autonomy and is associated with improvements in health care and patients’ health outcomes (Edwards, Davies, and Edwards 2009). Moreover, fostering patients' self-efficacy and autonomy led to greater information shared by patients, more negotiations, and enhanced dialogue. It implies a more fluid exchange of information, a more aware risk management by patients, raised locus of control and accountability, and more competent, effective health information use. Shared decision-making may improve the adherence and compliance of patients and their self-care and health behaviours by providing them a sense of ownership and control over their own lives and health. More details on this communication and shared decision-making between clinicians and patients are provided in the Section on *Counselling: Health communication in the medical consultation.*

Empowerment: empowered persons, empowered communities

Social relations are always framed within a socially determined power relationship. An undetermined and unknown degree of power imbalance is unavoidable - even undesirable - for conducting research and/or care; the empowerment/disempowerment pair does not propose equality between players with different roles which is, also, unreachable. Hence, the proposed definition relies on the foundational text *In Praise of Paradox: A Social Policy of Empowerment Over Prevention* (Rappaport 1981). While the concept of empowerment was founded before Rappaport's article, this suggests a dialectical model specifically aimed at public health interventions and research.

This article drafts two dialectical conflict models: prevention and advocacy or paternalistic or empowered care and participation. It is stated that prevention relies on the model of dependent people, the one-sided development of social services. Advocacy confronts this unilateral approach and proposes a new perspective based on a rights model of social responsibility:

> By empowerment I mean that our aim should be to enhance the possibilities for people to control their own lives. [...] We will, should we take empowerment seriously, no longer be able to see people as simply children in need or as only citizens with rights, but rather as full human beings who have both rights and needs. We will confront the paradox that even the people most incompetent, in need, and apparently unable to function, require, just as you and I do, more rather than less control over their own lives; and that fostering more control does not necessarily mean ignoring them. Empowerment presses a different set of metaphors upon us. It is a way of thinking that lends itself to a clearer sense of the divergent nature of social problems.
> (Rappaport, 1981; p.15)

Empowerment is understood considering three key elements: (i) counter-hegemonic rupture; (ii) advocacy; (iii) locus of control. At the community/social level, empowerment sometimes involves a rupture of the hegemonic order – or the status quo – in which counter-hegemonic forces/groups dispute their own rights and, thus, power in conflict with the ruling elite/s. This notion related to the rights and collective identity of discriminated minorities (e.g., ethnic minorities) implies deeper and substantial changes in the societal and systemic order itself (O'Campo and Dunn

2012; Griffin 2017). At the community level, empowerment as advocacy aims to raise individuals and communities' capacity to control their circumstances by exercising power framed in collective and collaborative efforts. In order words, and specifically applied to health promotion, it implies "identity, knowledge and understanding, personal control, personal decision-making, and enabling other patients" (Small et al. 2013). Finally, empowerment could have a more individualistic meaning, involving both sense of agency as *autonomy* and locus of control (Edwards, Davies, and Edwards 2009) and 'informed patient' or 'reflexive consumer'.

Counter hegemonic empowerment

Empowerment is a very complex concept that sometimes involves a rupture of the hegemonic order – or the *status quo* – in which counter-hegemonic forces/groups dispute their own rights and, thus, power, in conflict with the ruling elite/s; however, this notion related to the rights and collective identity of discriminated minorities (e.g., ethnic minorities or the LGBTIQ+ collective among others) implies deeper and substantial changes in the societal and systemic order itself that are not addressed by the notion used in the revised literature.

> A concept that refers to the giving or delegation of authority to someone to enable them to deal on their own or others' behalf. The empowerment of women has been a longstanding aim of feminism. As a concept, empowerment has become particularly prominent in feminist work on development and economics. Women's empowerment has been linked to their equality in the public and private spheres, to their right of participation and decision-making in those spheres, to their opportunities to become educated, become financially independent, and to make choices about their lives privately and publicly. In the 1970s empowerment was strongly linked to the notion of 'women doing it for themselves'; that is, the notion that women needed to empower themselves, rather than be empowered, to take control of their lives. In development studies it has been strongly linked to structural, institutional, and cultural reforms and changes, designed to give women equality within their communities.
>
> (Griffin 2017)

Empowerment as advocacy

Empowerment and advocacy opposite and defy the traditional model aimed at raising the capacity of individuals and communities to control their circumstances through exercising power framed in collective and collaborative efforts; in order words, and specifically applied to health promotion, implies "identity, knowledge and understanding, personal control, personal decision-making, and enabling other patients" (Small et al. 2013)

Empowerment requires social action and genuine involvement in the world:

> Empowerment implies that many competencies are already present or at least possible[...]. Empowerment implies that what you see as poor functioning is a result of social structure and lack of resources which make it impossible for the existing competencies to operate. It implies that in those cases where new competencies need to be learned, they are best learned in a context of living life rather than in artificial programs [...]
>
> (Rappaport, 1981; p16)

Empowerment as a locus of control

Due to the nature of the research in the field of health and the healthcare consultation given in a specific socio-historical context, there are not great ruptures, and shifts in the hierarchical relations and empowerment affect the interaction and relationships and, importantly, the ethical consideration of the research subject or the patient. Nowadays, the asymmetry and the imbalance of power cannot be broken.

> Structuring interaction and providing opportunities for clients to (a) obtain information about their situation, its causes, available strategies, and resources, and (b) become involved in managing their own life, including health condition and services, so that the person can take partial or total control of their affairs. Although an idea that is embedded in occupational therapy, it is contentious. Criticisms include questioning how and why people lose their right to autonomy, the power differential implicit in the idea of professionals enabling empowerment, and the assumption that every person wishes to take responsibility for their health
>
> (Molineux 2017)

Empowerment seems to involve the locus of control by an individual or a community (Edwards, Davies, and Edwards 2009); also in terms of 'informed patient' or 'reflexive consumer' – also, this notion could be linked with the 'prosumer' concept (See section 1 on the Theoretical Foundation). Thus, empowerment approaches the ability to make informed choices, manage risk, and seek information and involvement before, within, and after medical consultations. This notion of empowerment is linked to engagement: so, informed enhances patients' power and control over treatment decision-making.

Within this consideration, empowerment as an individual locus of control, refers to patients' capacities, knowledge, behaviour a.nd support by others (Pekonen et al. 2020).

Thus, empowerment could also be understood as a vague umbrella term opposing the social vs the individual-focused approach; i.e., comprising power and powerlessness dimensions (that are likely to reflect the actual social conditions) versus self-efficacy and control, commonly considered stable characteristics of the individual.

MATERIALS AND METHODS

Enhancing the impact of interventions in chronic health: a transnational qualitative meta-study
on sampling, recruiting and communication with vulnerable populations

This chapter aims at summarising the methods and materials used during the research process, including the explanation about the general framework and the decisions undertaken for conducting a meta-synthesis, the search strategy followed for finding the studies, the selection process and criteria for selecting the final sample, the procedures for extracting data, analysing the information and ensuring the quality and rigour of the research and, lastly, the overall characteristics of the papers included in the dissertation and the description of the sample of participants covered by these primary qualitative articles and dissertations included in the meta-study.

Section 1. General methodologic considerations

Objectives and research questions

The type of meta-study will be a qualitative synthesis in conjunction with the grounded theory principles; this innovative approach has been decided to ensure the (i) rigour and comprehensiveness of the analysis of the results, as well as the conclusions, models built and the implications for practice; and (ii) the effectiveness and agility of the GT in being applied to a very large sample of studies (n=103). Then, the start point is to define a set of research questions flexible but narrow enough.

The following table reflects the relationship between Research Questions, topics to be addressed and research phases:

Table 1 - Relation between Research Questions (RQ), topics and research stages

Research question	Topics to be addressed
RQ1 - Which are the main barriers and facilitators for communicating in health and, specifically, for obtaining information, recruiting hard-to-reach populations, and facilitating access to informal education initiatives on health literacy to raise collective and individual empowerment?	Research core: health communication and engagement of hard-to-reach patients with chronic conditions • Culturally competent interventions: sampling and recruiting in tailored interventions for chronic underserved patients. • Necessities and use of information obtained; lack of information management. • Communication with health professionals: roles, caring and self-caring in the medical consultation • Communication and co-production of research for informing practice at the community level: enhancing the end-users participation in CBPR Peer support and peer education; interpersonal relations in peers-based programmes and practice communities. Information and dissemination of chronic health on the Internet; ICT use and virtual communities
Research stages	• Qualitative synthesis within the Analysis (all sections) • Iterative and comparative analysis and Literature revision reflected on

	the Conceptual framework and the Discussion.
Specific-RQ2. How these barriers impact the self-management of chronic diseases, Specific-RQ3. How these barriers impact the health information obtained? Specific-RQ4. How these barriers impact its uses and the prognosis? Specific-RQ4.1. Conversely, what are the facilitators enhancing the self-management of chronic diseases and the acquisition of health information and how these impact on the individuals' health outcomes?	Health communication dimensions: intrapersonal and interpersonal communication. Value-neutrality and competing interests in determining and disseminating the research: science and society informing practice. Ethical challenges in community-based research. Efficacy and acceptability of communication; empowerment and self-management concepts.
Research stages	• Qualitative synthesis within the Analysis; specifically addressed within sections 2, 3 and 4 (health literacy, self-management and decision-making and empowerment, respectively) • Comparative analysis and Literature revision within the Conceptual framework and the Discussion
N/A – Transversal non-specific analysis	Multidimensional analysis of the 'social vulnerability' concept: systemic intersections and social determinants of health (SDH). The interaction between class-ethnicity-gender as regards health disparities: hidden populations and vulnerability as a gradient. Social class, ethnicity and social constructions on the concept of "race", gender, sex and identity
Research stage	• Theoretical foundation • Discussion • Literature revision and synthesis within the Theoretical foundation and the Discussion

Aligned with the research as mentioned above questions, the general objective, as described in the section on Introduction, is **to study the potential paths in natural clinical settings and within the social field to unveil the impact of vulnerability and discrimination and then the impact of empowerment on individuals and communities' health.**

Specific objectives are 3. Firstly, to determine how patient-provider communication can impact the engagement, involvement, and retainment in

healthcare, specifically for vulnerable patients with highly prevalent chronic conditions. The impact on patient-provider communication has been explored on Chapter 3 (Analysis and results) and specifically in Section 1 on Counselling and communication; in parallel, findings are addressed in detail and compared with the literate within Chapter 4, first section of the Discussion. However, given the iterative nature of the research and the wide-scoped impact on the patient-provider communication, related topics are addressed during the whole discussion and re-formulated within the conclusions for answering explicitly to the present objective. The first sub-objective focused on the effects of this communication on the patients' engagement in informal health education. The second sub-objective centres on the patients' self-management and self-care skills. Both sub-objectives are explored in sections 2 and 3 of Chapter 3 and further discussed in sections 2 and 3 of Chapter 4. In addition, the first objective is translated into practical recommendations within sections 1, 3, 5 and 6 of Chapter 5.

Directly related to the previous specific objective, the second objective is dedicated to unveil **the impact of joint decision-making on the patients' proactiveness in decision-making and how proactiveness** influence the acquisition of healthier habits and self-management routines. Secondary, the impact of joint decision-making in improving health outcomes. The analysis reflected on section 3 of Chapter 3 and, most important, section 3 of the discussion (Chapter 4) further responds to this specific objective, as well as the conclusions themselves, and provides recommendations on sections 5 and 6 of chapter 5.

The third specific objective aims at analysing the **barriers and facilitators** encountered by patients to **access health information in several contexts: counselling or** clinical consultation settings**, m**ass-media and traditional media**, c**ommunication campaigns in public health (both conducted by public or private entities, such as administrations or NGOs, respectively)**, r**esearch dissemination and communication, and all actions aimed at wide spreading the research results to the general society**, h**ealth education and health literacy programmes, including also mutual support groups**, or c**ommunity-based settings and community initiatives. Given the iterative and broad approach of the present dissertation, the specific objective was analysed, discussed and translated into recommendations for practice within the entire thesis, not being possible to restrict their response to specific sections (except the Conclusions).

The last specific objective was to **operationalise the "social vulnerability" concept** in light of well-established sociological relational theories for being applied in the present research but, most important, in the application and comprehension within clinical practice in real-world settings. The theoretical framework and the conceptual framework, iteratively developed within the entire duration of the present research, reflect the results of this objective: the theoretical framework proposes a final inter-sectional perspective for analysing and utilising the broad concept of "social vulnerability"; separately, the conceptual framework and, specifically the Section 2, point 2.1. The socioecological model schematises the general analytic framework for exposing the analysis results in chapters 3 and 4.

Methodology

This research consists of a meta-synthesis. Meta-synthesis are able to approach a vast range of studies – including culturally-comprehensive interventions and complex procedures – while also building new concepts and lines of argument supposing an innovative approach and contributions to the field, in this case, of health communication and education for hard-to-reach communities and chronic diseases. Qualitative research gives insight on the main topics and themes concerning this PhD dissertation, considering the metaphors, customs and use of all participants in their own words. Being the main topic 'health communication' - specifically related to recruitment and engagement of chronic and underserved patients from several cultural backgrounds - we considered that primary qualitative studies including text units as main content to research provide us with the information in an adequate way.

Meta-synthesis can merge, analyse, synthesise and built new knowledge and frameworks based on culture variations and text-units (contributions and excerpts included in the research) done by participants; these contributions are hardly reduced to quantitative units and are not measurable themselves. Moreover, the use of very heterogeneous evaluation instruments and scales complicates the quantitative analysis and there is no evidence about the inter-comparability of these scales, some of them non-validated.

In sum, this methodology follows the **Noblit and Hare** phases (Noblit and Hare 1999; Bondas and Hall 2007; Sandelowski, Docherty, and Emden 1997)

Phase 1: Getting started
Identifying an intellectual interest that qualitative research might inform
Phase 2: Deciding what is relevant to initial interest
Searching for studies to be included
Phase 3: Reading the studies
Repeated re-reading of studies to identify concepts/ metaphors
Phase 4: Determining how the studies are related
Determining the relationships between the studies
Phase 5: Translating the studies into one another
Comparison with metaphors/ concepts in one study with those in other studies. Translations can be reciprocal, refutational, or form a ”line-of-argument”
Phase 6: Synthesizing translations
Secondary translation (not always possible) when translations can encompass those of other accounts producing third-order constructs?
Phase 7: Expressing the synthesis
Communication of the findings from the meta-ethnographic synthesis in a form appropriate for the audience

This meta-study only includes papers and MsC.Dissertations and PhD thesis because of the quality assurance mechanism behind and for assuring that the sample collected is relevant for the research purpose.

Studies included are (1) primary and (2) qualitative. Its quality will be assessed through the Critical Appraisal Skills Programme <https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-Download.pdf> , widely used in meta-ethnographic research. Before filtering papers and PhD dissertations using the CASP instrument, duplicates and non-directly related articles were deleted to assure the relevance for the synthesis.

1. **Definition of the research topic**.

The first research questions were formulated. A narrative and interpretative review of the literature from a sociological and philosophical perspective was conducted for 6 months.

2. **Definition of the search strategy**

The literature search was conducted in the University of Valencia database (Trobes) and Google Scholar. Trobes includes Cochrane Library, SCOPUS, Web of Science, Journal Citation Reports, MedLine, Proquest Central or Proquest

Dissertations and theses, among others, specified at http://trobes.uv.es/search*spi/. Google Scholar was used to find peer-reviewed grey literature, avoiding publication bias. The following keywords were used in both databases:

- Qualitative study
- Health communication
- Recruitment
- Empowerment
- Engagement
- Chronic
- Long-term condition
- Participation
- Vulnerable
- Recruitment
- Hard-to-reach

Two searches were carried out primary search with the terms *((qualitative study) OR (experience)) AND ((health communication) OR (health dissemination)) AND (recruitment) AND (empowerment) AND ((chronic) OR (long-term condition))* and a secondary one, including exclusion criteria, with *(health communication) AND ((recruitment) OR (engagement) OR (participation)) AND ((vulnerable) OR (hard-to-reach)) AND (qualitative) AND (chronic diseases) AND (systematic review) NOT (meta-synthesis) NOT (meta-analysis) NOT (elderly) NOT (children) NOT (developing countries).*

3. **Deleting duplicates**

Bibliographical databases often offer a wide range of duplicated results; after exporting to Zotero all resulting references from the two literature searches (primary and secondary), duplicates were deleted. Non-related results were deleted as well.

4. **Definition of the eligibility criteria**

As Figure 10 explains, initial results showed 4026 references (3559 after deleting duplicates; 2729 after deleting irrelevant and non-related results) from 2008 to 2018, comprising the economic and financial period crisis. Since financial crises imply limited resources devoted to health promotion, investigating how to foster health communication, literacy, self-management, empowerment and co-production in a period of crisis has a clear intrinsic interest.

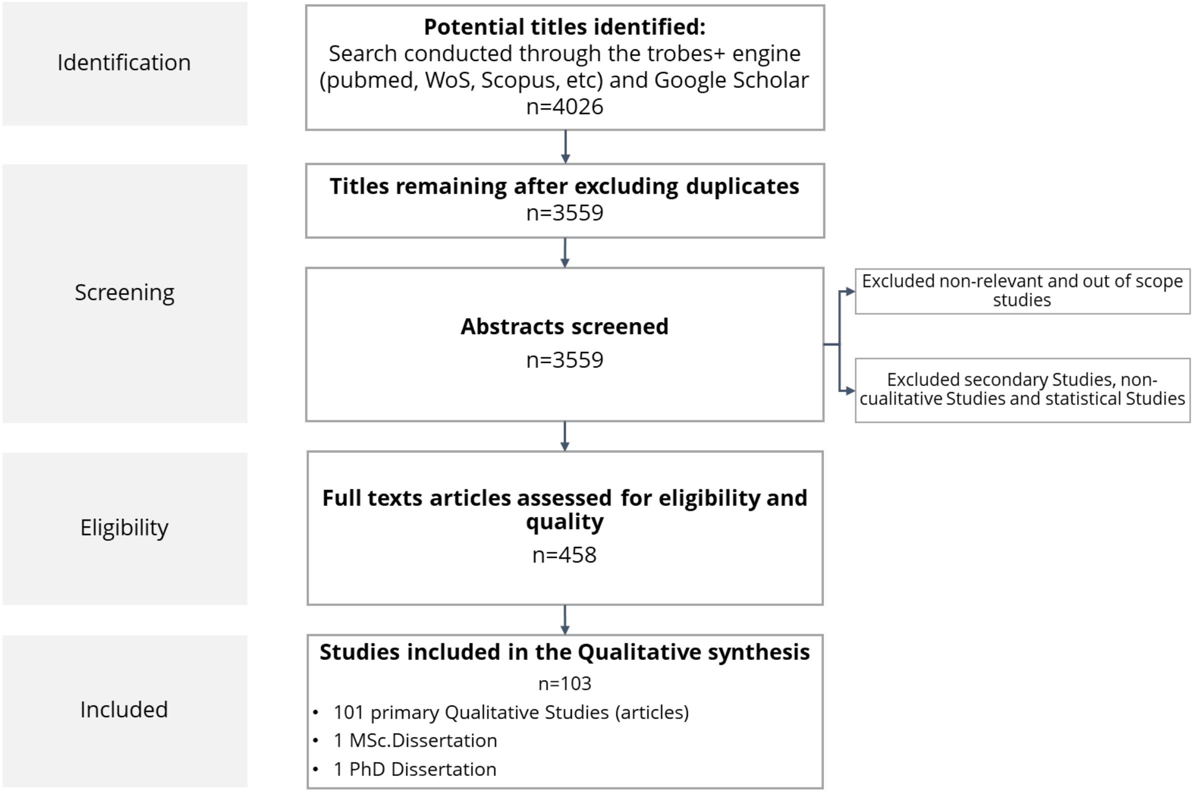

Figure 10 - Flow chart: search strategy and results

Table 2 - Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
✓ Peer-reviewed (articles, PhD dissertations…) ✓ Primary study ✓ Qualitative study ✓ Mixed method study ✓ From 2008 to 2018 (economic crisis and partial recovery) ✓ High-Income Countries (transferability of results) ✓ Adult populations (18 – 65 years old) ✓ In situations of psycho-social vulnerability ✓ CASP≥8	▪ Conflict of interest declared. ▪ Not clear sample of participants.

Then, 2729 abstracts were imported to Zotero and, then, to MAXQDA, for being screened attending to the type of study and the relevance of the papers.

5. **Reading abstracts and deciding relevance:** Then, all titles and abstracts were analysed and the most relevant ones were selected. Three groups were formed: papers included in the first selection, potentially related papers that could aid the theoretical framework, theory-building papers (such as MA, MSs or systematic reviews, but not restricted to these types of research) that will sustain the conceptual framework. The relevance analysis was finalised on the 14th of May 2018. In the preparatory phase, research can be addressed through concepts. However, tabs will be grouped by fields, topics, categories and processes.

After the screening, 458 studies met the eligibility criteria:

- **Types of articles:** qualitative research; primary studies. Models, SR, MA and MS shall be used for the conceptual framework. Papers without conflict of interest. Theoretical assumptions and perspectives clearly stated. The appropriate study population (see Types of participants).
- **Publications published** on academic or research Journals (trobes+), conference proceedings (google scholar) and working papers (research gate) from 2008 to 2018 (start of the crisis, so, hypothetical changes as regards health systems, socio-educative intervention and any 2008=other initiative focused on prevention, patients' empowerment or behavioural change)
- **Types of participants**: Adults with chronic conditions, vulnerable and/or at risk of social exclusion; Physicians, practitioners and health professionals. Researchers in the field of public health or social epidemiology conducting studies through CBPR methods. Geographical restriction: HIC and systems sufficiently similar to the current European context
- **Type of data:** qualitative data directly obtained from participants. Comments and texts by the researchers or studies' authors.
- **Relevant outcomes**: Opinions and beliefs of participants about health and behavioural change applied to health-related behaviours. Impressions and experiences on communication between practitioners/nurses/other HP and patients (bidirectionally). Experiences in offline or online communities of patients. Experiences on non-formal and informal health education (by professionals or by a patient or any

other participant relevant for the research purpose). Opinions, experiences, and lessons learnt by researchers trying to conduct a study based on the CBPR methodology.

458 studies were scanned and assessed for the final selection, considering the inclusion criteria. and the quality control through the Critical Skills Programme (CASP) questionnaire for qualitative research papers. A data base with the CASP items, the total punctuation of each paper and the following exclusion criteria was created: a) conflict of interest; b) primary qualitative; c) part of a RCT (not mandatory, but convenient); d) includes quotations? (not mandatory). The database also includes basic information about the place of publication and research, topic, illness (if any), sample and type of participants.

6. **Building concepts (part 1)**: All abstracts from the preliminary selection (458 articles and PhD dissertations) were analysed: qualitative data will be exploited using a set of concepts for emerging the first conceptual approach and defining the definitive screening questions related to relevance. Screening questions are Year, Place, Illness, Topic, Sample, Type of participants, Type of study, Conflict of interest declared and Integration of quotations or excerpts, transcribed verbatim.

Main screening questions

- **Year**: the qualitative synthesis will include only research from 2008 to 2018, so research coincided with the financial crisis, as long as financial crisis might suppose a barrier as regards human and material resources devoted to health promotion. This time frame does not affect the theoretical and the conceptual framework
- **Place**: only studies conducted in the developing world are included because research in this field carried out in LMIC (Low and Medium Income Countries) is not easily transferable to our settings
- **Illness or disease:** only chronic conditions are included. End-users of interest are vulnerable adult persons with chronic diseases. The vulnerability concept is furtherly defined in the theoretical framework.
- **Topic or theme:** main area of interest or research of the paper. This screening question only responds to classificatory aims.
- **Sample** (n): sample does not determine quality, but sample responds to classificatory aims too; if the number of men and women is specified, it will be considered. In addition, gender of contributing researchers will be taken into account for the final sample of papers selected within the meta-study.
- **Type of participants**: specifies the type of participants; e.g., health professionals, patients, etc.
- **Type of study:**

    - Is it a primary qualitative study?: Primary qualitative studies are preferred as a source of information, while mixed-methods papers are not excluded.
    - Is it a randomised controlled trial (RCT), or is it framed within an RCT? RCT constitutes one of the highest levels of evidence; in these fields, some RCTs include qualitative research. RCTs including qualitative research are preferred as a source of evidence.
- **Is there any conflict of interest declared? Is this paper funded?** Funding does not exclude any research paper or PhD Thesis, but it is important to understand each research's aims and scope within a certain geo-strategic and political context. Papers with conflict of interest will be excluded.
- **Does it include phrases, statements, excerpts, or any other transcript directly from the participants?** Primary data, while the researchers interpret it, is very valued for this meta-study as it provides first-hand knowledge and raw expressions and, as a consequence, metaphors and deep experiences yet validated by peer reviews in the case of Journals.

7. **Deciding relevance:** CASP criteria were applied to all articles and PhD Thesis for assessing quality; relevance of papers and dissertations will be assessed to **screening questions** formulated before. Papers will be excluded if the answer to the first question of the CASP questionnaire is NO ("Was there a clear statement of the aims of the research?")
   Finally, 103 studies meeting all inclusion criteria and rated as excellent (CASP≥8) were retained in the final sample (Figure 10 - Flow chart: search strategy and results**)**
8. **Synthesizing qualitative, relevant and primary research**, once high-quality contributions have been selected (because it seems more useful to consider the value of the paper to the synthesis and exclude poor-quality papers at the synthesis stage) an iterative process for analysing and synthesising qualitative research starts. "The concepts identified during the appraisal process were the raw data for the first synthesis stages. The distinction between concepts and themes is blurred, but we defined concepts as having some analytic or conceptual power, unlike more descriptive themes.
9. **Organising findings into groups:** how the studies and results are related to one another?
10. **Translating studies into each other (within groups) or *reciprocal translations*:** have concepts/metaphors different "labels" or are these describing the same idea?
11. **Determining how findings relate to each other.** It implies summarising concepts of each group and trace relationships between them

12. **Determining how studies and their findings are related across groups. I**t allows to draft and trace models providing a useful map of the synthesis
13. **Synthesizing translations across groups and creating a middle-range theory**. It requires to compare textual translations for each group by reading and re-reading each of the reciprocal translations and analysing thematically the data find out. It produces a line-of-argument synthesis and reconceptualises the findings. **This line-of-argument is a middle-range theory for being tested in other settings, conditions or contexts.**

Lastly, the steps 8 to 11 emerged in four dimensions:

1. Communication and counselling
2. Health education and health literacy programmes
3. Adherence, self-management of health and decision-making
4. Individuals and communities' empowerment

Within each category, enablers and barriers were differentiated, as well as the emerging themes; for the analysis, the socio-ecological model was used to unveil the key determinants and factors influencing each dimension at micro, meso and macro levels.

The process for advancing from step 8 to step 13 is detailed on the

Section 2. Data extraction, analysis and quality control.

Section 2. Data extraction, analysis and quality control

PDFs (full texts of each article) were downloaded. Both the full paper as well as the section on *Results* were coded and analysed using the MAXQDA (Verbi® v2018-2020) following a meta-synthesis method (Noblit and Hare 1999; Bondas and Hall 2007; Sandelowski, Docherty, and Emden 1997)merged with grounded theory techniques in order to maximise the effectiveness of the theory-building process through the spontaneous emergence of themes, metaphors and meanings.

The grounded theory analysis relies in the lack of predefinition of the themes extracted. The qualitative data is tagged according to those repeated ideas and iterative concepts emerging, following and inductive reasoning led by the materials themselves in order to generate middle-range theories (Sandelowski, Docherty, and Emden 1997)The analysis was conducted on the 103 studies selected.

Specifically, measures implemented for meeting the quality and rigour criteria for qualitative research (Baillie 2015) during this investigation were:

- **Credibility** and **truth-value,** ensured through making clear and explicit all potential biases during the data analysis and the illustration of data analysed and synthesised. Also, the credibility of the research results is sustained by meaningful examples during the reporting phase (e.g., the chapter on analysis and results). Fields notes, memos and thematic logs were kept clarifying to which extent the subjectivity may interfere in the interpretation.

In order to document potential biases during the subsequent readings of the material, a Research Diary was created and updated during the coding and the analysis process, accomplishing the self-reflection required in order to ensure the rigour in qualitative research and, moreover, in synthesis research, which necessarily involve new constructs and introduces the researcher’s subjectivity.

- **Transferability**, which is characterised by the applicability of the results in other contexts (e.g., in real settings and further works on counselling or decision-making), through controlling and documenting the search strategy, decisions made during the process, the evaluation methods for selecting the studies included and the sample. A simultaneous literature review was conducted iteratively, reflected in the theoretical framework and the discussion chapters.

- **Reflexivity.** Through researchers' reflexivity, appropriately documented, and quality control by parties involved (director and co-director), Dependability or consistency is achieved through researchers' reflexivity. This criterion's ultimate goal is to reduce the data instability, assuming that instability itself is not avoidable.
- **Confirmability**, given through the intended neutrality and sincere awareness of subjective elements during the analysis and synthesis of results. Also, it is given by making explicit the theoretical positioning of the researcher.

Codes and thematic areas

Codes arose during the analysis process, emerging from the texts and the ideas and representations sustained by all studies analysed. Literal quotations coded are annexed in the annex attached.

The analysis process started since the early beginning of the research through the abstract and papers scanning; abstracts of 458 papers were read and codified informally to obtain a vast range of general and unstructured information concerning themes and main fields of research, categories and thematic areas. Then, once the papers were evaluated under the quality criteria explained in the next section 4 on Characteristics of the papers selected, the resulting 103 papers, included in the sample, were read without coding.

The following interaction involved a preliminary codification, discussed among all colleagues in Kveloce I+D+i in the company's meeting in July 2018. Then, considering the informal discussions and feedback received about the code structure and the preliminary relations established among codes, a more methodologically comprehensive strategy was used for the second iteration, reaching 4 key themes and their subsequent coding: communication and counselling, health literacy, self-management and decision-making, and empowerment; an additional theme arose as well, on research. The last theme on research was analysed separately and published as a research study [REF]

Lastly, a third iteration involved the classification of all factors that emerged into barriers and facilitators, or advantages and disadvantages depending on the nature of the topic and participants' interventions; the last phase of the analysis was performed through the word processor (MSWord®) instead of the qualitative analysis software, for analysing and obtaining results on which factors at micro, meso and macro levels are critical for each of the analysed themes; in addition, the last phase involved to separate the section on IT tools from the self-management one (in which was previously included), considering that IT tools may be treated and reflected as a transversal result.

To sum up, codes were:

Node / code	**Fragments codified**
1 Communication in clinical settings	0
1.1 Communication patients-HPs	0
1.1.1 Barriers in the communication HCPs-Patients	0
1.1.1.1 lack of communication skills, harsh, paternalistic communicatio	197
1.1.1.1.1 paternalism	33
1.1.1.2 Unclear and little information	186
1.1.1.3 overwhelmed!	47
1.1.2 Facilitators in the communication HCPs-Patients	0
1.1.2.1 Humanisation of care, caring persons	97
1.1.2.1.1 Trust, know the truth and full info	96
1.1.2.1.2 Communicating is caring	390
1.1.2.1.3 Mutual respect	61
1.1.2.1.4 Feeling useful	68
1.2 Communication between HPs: teaming and its impact for patients	25
1.2.1 Facilitators in the communication between professionals	46
1.2.2 Barriers in the communication between professionals	33
1.2.3 culture and education are related to communication between HPs	23
2 Health education and health literacy	0
2.1 Health literacy	1
2.1.1 Facilitators: accessing to info, health literacy	245
2.1.2 Barriers: accessing to info, health literacy	78
2.2 Health education programmes	0
2.2.1 Engaging in health prom & ed: comments	9
2.2.2 Facilitators: health education & mutual support	204
2.2.2.1 Recommendations for engaging persons in health education	248
2.2.2.2 Recruiting users for health promotion/education	111
2.2.3 Barriers: health education & mutual support	126
3 Decision-making and self-management	0
3.1 Compliance and adherence	0
3.1.1 Facilitators: Compliance and adherence	92
3.1.2 Barriers: Compliance and adherence	115
3.1.3 Self-management	0
3.1.3.1 self-management	203
3.1.3.2 Facilitators: self-management	140
3.1.3.2.1 IT, eHealth and mHealth	179
3.1.3.3 Barriers: self-management	178

3.2 Decision-making	223
3.2.1 Facilitators: decision-making	213
3.2.2 Barriers: decision-making	97
3.2.2.1 low self-efficacy (patient!), fear of being control	120
3.2.2.1.1 My time, my life, is not so important...	17
3.2.3 reluctance to disclose info, d/mistrust, fear institutions	60
3.3 How participants heard about interventions, technologies, etc.	15
3.4 Empowerment	0
3.4.1 Between empowerment, responsibility and guilt	0
3.4.1.1 Sense of agency	125
3.4.1.2 Feelings and diagnosis	208
3.4.1.3 Responsibility	44
3.4.1.4 Guilt	31
3.4.2 Collective empowerment, empowered communities	0
3.4.2.1 Facilitators: empowerment	103
3.4.2.2 Barriers: empowerment	120
4 PPI/E and research	0
4.1 Researching in health and in the community	0
4.1.1 Facilitators for researching	94
4.1.2 Barriers for researching	103
4.2 Patients participating in research ,PPI and PPE	0
4.2.1 Facilitators for getting engaged in research ,PPI and PPE	230
4.2.2 Barriers for getting engaged research ,PPI and PPE	86
4.2.3 Recruitment for research	0
4.2.3.1 Facilitators for recruiting in research projects	91
4.2.3.2 Barriers for recruiting in research projects	39
5 Systemic co-determinants and specific difficulties	1
5.1 Specific situations, specific strategies!	0
5.1.1 Gender	0
5.1.1.1 gender issues, general	19
5.1.1.2 Feminity	332
5.1.1.3 masculinities	166
5.1.2 Queer and Sexual Minorities	178
5.1.2.1 Sex workers	16
5.1.3 Disability	6
5.1.4 Culturally and linguistically diverse groups	213
5.1.4.1 Migrants	139
5.1.4.2 Communication with non-native speakers	169
5.1.5 Poverty & low income, low SEP	147
5.1.6 Diagnosis of mental disorder	22
5.1.7 rural, small town	32
5.1.8 Drugs, addictions	22
5.2 Racialised communities	262
5.3 System makes things easier or even worse	224
5.3.1 Integration and continuity of care is very important	197
6 How researchers recruited people for the study	136
7 Theoretical insights	157
8 VERDE	17

In parallel, the following themes arose:

- Communication and counselling
- Health education and health literacy programmes
- Adherence, self-management of health and decision-making
- Individuals and communities' empowerment

Also,

- Co-production in research, analysed separately and published independently
- IT tools and the Internet, separated from its initial parent theme on Self-management.

The construction of lines of argument and, then, the theory-building and its comparison and discussion with current literature and theoretical foundations was a permanent and iterative process as well but was mainly framed during the last stages of the analysis and, especially, during the elaboration of the discussion.

The finalisation of the Discussion supposed to update and simplify the Theoretical Framework and, most importantly, the Conceptual Framework.

Section 3. Characteristics of the papers selected for the meta-synthesis

Studies included and type

Finally, 103 studies have been included: among them, 100 were qualitative research papers published in Journals, 2 were PhD dissertations, and 1 of them was a MsC dissertation.

Table 3 – Studies by type

CO01 Sacks, A. Abt et al. - 2016	Qualitative – Research Paper
CO02 Dellasega, Cheryl et al. - 2011	Qualitative – Research Paper
CO04 Delea, Sarah et al. - 2015	Qualitative – Research Paper
CO05 Mota, Lorena et al. - 2015	Qualitative – Research Paper
CO06 Graves, K. et al. - 2011	Qualitative – Research Paper
CO07 Alexander, Stewart C. et al. - 2012	Qualitative – Research Paper
CO08 Dowling, Joni E. - 2010	PhD Dissertation
CO09 Laws, M. Barton et al. - 2012	Qualitative – Research Paper
CO10 Burridge, Letitia H. et al. - 2011	Qualitative – Research Paper
CO11 Meyer, Samantha B. et al. - 2012	Qualitative – Research Paper
CO12 Rubio-Rico, Lourdes et al. - 2014	Qualitative – Research Paper
CO13 Venetis, Maria K. et al. - 2018	Qualitative – Research Paper
CO14 Hersch, Jolyn et al. - 2013	Qualitative – Research Paper
CO15 Hart, Ruth I. et al. - 2017	Qualitative – Research Paper
CO17 Garon, M. - 2012	Qualitative – Research Paper
CO19 Brez, Sharon et al. - 2009	Qualitative – Research Paper
CO20 MacDonald, Kath et al. - 2015	Qualitative – Research Paper
CO21 Berry, Judith A. - 2009	Qualitative – Research Paper
CO22 Smith, Sian K. et al. - 2008	Qualitative – Research Paper
CO23 Davies, Jane et al. - 2014	Qualitative – Research Paper
CO26 Wray, Ricardo J. et al. - 2009	Qualitative – Research Paper
CO27 Dolce, Maria C. - 2011	Qualitative – Research Paper
CO29 Reimann, Swantje et al. - 2010	Qualitative – Research Paper
CO31 Zulman, Donna M. et al. - 2015	Qualitative – Research Paper
CO32 Greenhalgh, Trisha et al. - 2010	Qualitative – Research Paper
CO33 Vilhauer, Ruvanee P. - 2014	Qualitative – Research Paper
CO35 Goddu, Anna P. et al. - 2015	Qualitative – Research Paper
CO36 Wilkinson, Emma et al. - 2014	Qualitative – Research Paper
CO37 Taylor, Elizabeth et al. - 2014	Qualitative – Research Paper
CO38 Duineveld, Laura A. M. et al. - 2016	Qualitative – Research Paper
ED10 Costello, Joanne F. - 2013	Qualitative – Research Paper
ED11 Dale, Jeremy et al. - 2008	Qualitative – Research Paper
ED12 Caine, Vera et al. - 2016	Qualitative – Research Paper
ED13 Nunes, Julie A. Wright et al. - 2015	Qualitative – Research Paper
ED14 Vega, Gema et al. - 2014	Qualitative – Research Paper
ED15 Goebbels, Adrienne F. G. et al. - 2012	Qualitative – Research Paper
ED16 Wright, Nicola - 2013	Qualitative – Research Paper
ED2 Barlow, J. H. et al. - 2009	Qualitative study framed within a RCT – Research paper
ED4 Blixen, Carol et al. - 2015	Qualitative – Research Paper
ED5 Albarran, Cynthia R. et al. - 2014	Qualitative – Research Paper
ED6 Burda, Marika H. F. et al. - 2012	Qualitative – Research Paper

ED7 Hurt, Tera R. et al. - 2015	Qualitative – Research Paper
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	Qualitative – Research Paper
ED9 Santos-Livengood, Christie A. - 2015	MsC Dissertation
EM01 Agerskov, Hanne et al. - 2015	Qualitative – Research Paper
EM02 Miller, Robin Lin et al. - 2012	Qualitative – Research Paper
EM03 Goldenberg, Shira M. et al. - 2016	Qualitative – Research Paper
EM04 Boise, Linda et al. - 2013	Qualitative – Research Paper
EM05 Oliffe, John L. et al. - 2008	Qualitative – Research Paper
EM06 Phillips, Janice et al. - 2011	Qualitative – Research Paper
EM07 Bhattacharya, Gauri - 2012	Qualitative – Research Paper
EM08 NANTON, V. et al. - 2011	Qualitative – Research Paper
EM09 Grande, Stuart W. et al. - 2013	Qualitative – Research Paper
EM10 Peterson, Jennifer L. et al. - 2012	Qualitative – Research Paper
EM11 Nota, Ingrid et al. - 2016	Qualitative – Research Paper
EM12 Wiljer, David et al. - 2013	Qualitative – Research Paper
EM13 Kowitt, Sarah D. et al. - 2015	Qualitative – Research Paper
EM15 Taylor, Francesca et al. - 2016	Qualitative – Research Paper
EM16 Vries, D. H. de et al. - 2016	Qualitative – Research Paper
EM17 DiGiacomo, M. et al. - 2015	Qualitative – Research Paper
EM18 Rivas, Carol et al. - 2012	Qualitative – Research Paper
EM19 Bess, Kimberly D. et al. - 2009	Qualitative – Research Paper
EN01 Ekundayo, Olugbemiga T. et al. - 2012	Qualitative – Research Paper
EN02 Browne, Annette J. et al. - 2012	Qualitative – Research Paper
EN03 Locock, Louise et al. - 2011	Qualitative – Research Paper
EN04 Cook, Catherine - 2012	Qualitative – Research Paper
EN05 Graffigna, Guendalina et al. - 2014	Qualitative – Research Paper
EN06 Walters, Chasity Burrows - 2013	Qualitative – Research Paper
EN07 Hout, Marie Claire Van et al. - 2012	Qualitative – Research Paper
EN08 Carlisle, Karen et al. - 2017	Qualitative – Research Paper
EN09 Flournoy, Minnjuan W. - 2011	PhD Dissertation
EN10 Brooks, Fiona - 2008	Qualitative – Research Paper
EN11 de Wit M, Abma T et al. - 2013	Qualitative – Research Paper
EN12 Kraemer, A. et al - 2015	Qualitative – Research Paper
EN14 Hirjaba, Marina et al. - 2015	Qualitative – Research Paper
EN15 Maten-Speksnijder, Ada J. et al. - 2016	Qualitative – Research Paper
EN16 Holmberg, Christine et al. - 2015	Qualitative – Research Paper
EN17 Bailey, Kenneth Chase et al. - 2014	Qualitative – Research Paper
EN18 Mitchell-Brown, Fay et al. - 2017	Qualitative – Research Paper
EN19 Garcia, Jonathan et al. - 2015	Qualitative – Research Paper
EN20 Pinto, Rogério M. - 2009	Qualitative – Research Paper
EN21 Buck, Deborah et al. - 2014	Qualitative – Research Paper
EN23 Davies, Freya et al. - 2014	Qualitative – Research Paper
EN24 Powell, Rhea E. et al. - 2016	Qualitative – Research Paper
EN25 Robinson, Nicola et al. - 2015	Qualitative – Research Paper
EN26 Abma, Tineke A. et al. - 2015	Qualitative – Research Paper
EN28 Safo, Stella et al. - 2016	Qualitative – Research Paper
EN29 Richardson, Lorilei M. et al. - 2016	Qualitative – Research Paper
EN30 Cook, Erica J. et al. - 2014	Qualitative – Research Paper
EN32 Hogden, Anne et al. - 2012	Qualitative – Research Paper
EN33 McDonald, Ruth et al. - 2008	Qualitative – Research Paper
EN34 Natale, Anthony P. - 2009	Qualitative – Research Paper
EN35 Gien, Lan et al. - 2017	Qualitative – Research Paper
EN36 CLOCHESY, JOHN M. et al. - 2015	Qualitative – Research Paper
EN37 McCabe, Catherine et al. - 2014	Qualitative – Research Paper
EN38 Ross, Fiona et al. - 2014	Qualitative – Research Paper
EN39 Durme, Thérèse Van et al. - 2014	Qualitative – Research Paper
EN40 Rise, Marit By et al. - 2013	Qualitative – Research Paper

EN41 Thompson, Jill et al. - 2014	Qualitative – Research Paper
EN42 Fairbrother, Peter et al. - 2013	Qualitative – Research Paper
EN43 James, Delores C. S. et al. - 2017	Qualitative – Research Paper
EN44 Gagnon, et al - 2014	Qualitative – Research Paper
EN45 Young, C. et al. - 2016	Qualitative – Research Paper

Studies by participants and type of sample

The sample analysed in the 103 studies selected covered qualitative data from , at least, 5076 individuals. However, some specific figures remain unclear since some research papers conducted a participatory observation of very large samples. The sample remains unclear because the audience of these meetings cannot be easily specified. Besides, 37 reports were included by the researchers, 16 visits to stakeholders and 10 organisations were studied.

By type, the individuals (more than 5076) are explored in the following table:

Table 4 - Studies by sample of individuals

Respondents: unclear sampling or type not specified	54
Health care professionals (HCPs)	909
FEMALE HCPs	249
MALE HCPs	93
GENDER NON SPECIFIED - HCPs	567
HCPs by type or specialisation	
General practitioners	121
Cardiology specialists	3
Medicine	9
Nurses	217
Palliative care specialists	15
Oncologists	8
Surgeons	8
Genetic counsellors	5
Obstetrist/Gyn	2
GPs organisations	6
Other	84
Other players involved in health care, excluding HCPs in-service	360
Managers	44
Health worker	6
Allied health professional	2
Administrator	5
Academics, researchers	92
Educator	1
Social Worker	24
Community members, leaders	51
Key informants (non-specified)	42
Elected officials	2
Journalists	2
Cleargy	2

Business	19
Others	41
Public admon	25
Policy specialist	2
Caregivers	33
FEMALE CAREGIVERS	23
MALE CAREGIVERS	5
CARERS and relatives (GENDER NON-SPECIFIED)	5
Diads of patients and caregivers	501
Mediators	6
Female mediat ors	5
Male mediators	1
Materials quoted, cited	N/A
Workshop, meetings reports	45
reports, trials, projects	37
Visits to stakeholders, various	16
Websites	21
Civil Society organisations and associations/advocacy groups	N/A
Indigenous people (role not confirmed)	24
PATIENTS REPRESENTATIVES	20
Organisations, groups (various)	28
Pharmacist organisations	3
Patients	3263
FEMALE PATIENTS	1401
MALE PATIENTS	1632
TRANS, QUEER	3
PATIENTS (GENDED NON-SPECIFIED)	227
Patients by ethnicty	
Non-Hispanic white	452
Hispanic or Latino	149
Arabs/Maghreb	69
Asian	59
Black	349
American Indian/Alaskan Native	5
Native Hawaiian/Pacific Islander	2
UNKNOWN	187
Patients by disease, illness or disorder	
T2D	231
T1D	45
DIABETES - TYPE NON-SPECIFIED	40
HIV - AIDS	625
OTHER STIs	26
Stroke	0
Renal	27
CVD	76
cystic fibrosis	10
Long term conditions (various)	9
Mental health problems	2
COPD	70
CANCER (other and non specified)	32
CANCER: Colo-rectal	43
CANCER: PROSTATE	352

CANCER_ Gynaecological	17
CANCER: BREAST	243

To summarise, considering a total sample of > 5076 individuals:

- >909 healthcare professionals (HCPs) were covered, being the most represented the nurses and the GPs. >360 persons involved in healthcare but not being in-service HCPs were involved in the studies.
- More than 33 caregivers participated and 501 dyads of caregiver-patient
- 6 intercultural mediators are covered by the studies
- Concerning materials, 45 workshops, 37 trials and projects, 16 visits to stakeholders and 21 websites were analysed in the studies included in the sample
- In regards the civil society representativeness, 24 indigenous persons (role not confirmed), 20 patients' representatives and 28 organisations appeared. 3 Pharmacists Organisations were also included.
- More than 3263 patients were included, reaching a gender balanced sample (>1401 females, >1632 males, at least 3 queers or non-binary persons and >227 non-specified). By ethnicity, non-Hispanic white (>452), Black (>349, including African American persons) and Hispanic (149) are the most represented. By disease, it is worth to mention that HIV-AIDS (625), Prostate (352) and Breast (243) cancers and Type 2 Diabetes or T2D (231) seems to be the most exemplified groups.

Studies by country

By country, studies are predominantly anglo-saxon, finding some EU-based studies, multinational research and, also, studies from Australia or New Zealand.

Figure 11 - Countries representativeness

Table 5 explicitly details the geographical coverage of studies included:

Table 5 - Studies by country/countries and geographical coverage of the sample

Study	Country
CO01 Sacks, A. Abt et al. - 2016	SPAIN
CO02 Dellasega, Cheryl et al. - 2011	USA
CO04 Delea, Sarah et al. - 2015	IRELAND
CO05 Mota, Lorena et al. - 2015	CANADA
CO06 Graves, K. et al. - 2011	USA
CO07 Alexander, Stewart C. et al. - 2012	USA
CO08 Dowling, Joni E. - 2010	USA
CO09 Laws, M. Barton et al. - 2012	USA
CO10 Burridge, Letitia H. et al. - 2011	AUSTRALIA
CO11 Meyer, Samantha B. et al. - 2012	AUSTRALIA
CO12 Rubio-Rico, Lourdes et al. - 2014	SPAIN
CO13 Venetis, Maria K. et al. - 2018	USA
CO14 Hersch, Jolyn et al. - 2013	UK
CO15 Hart, Ruth I. et al. - 2017	UK
CO17 Garon, M. - 2012	USA
CO19 Brez, Sharon et al. - 2009	CANADA
CO20 MacDonald, Kath et al. - 2015	UK
CO21 Berry, Judith A. - 2009	USA
CO22 Smith, Sian K. et al. - 2008	AUSTRALIA
CO23 Davies, Jane et al. - 2014	NETHERLANDS, RUSSIA, NORWAY, CHINA (HONG KONG), WALES, GERMANY AND POLAND
CO26 Wray, Ricardo J. et al. - 2009	USA
CO27 Dolce, Maria C. - 2011	USA
CO29 Reimann, Swantje et al. - 2010	GERMANY; INTERNATIONAL
CO31 Zulman, Donna M. et al. - 2015	USA
CO32 Greenhalgh, Trisha et al. - 2010	UK

CO33 Vilhauer, Ruvanee P. - 2014	USA
CO35 Goddu, Anna P. et al. - 2015	USA
CO36 Wilkinson, Emma et al. - 2014	UK
CO37 Taylor, Elizabeth et al. - 2014	UK
CO38 Duineveld, Laura A. M. et al. - 2016	NETHERLANDS
EN01 Ekundayo, Olugbemiga T. et al. - 2012	USA
EN02 Browne, Annette J. et al. - 2012	CANADA
EN03 Locock, Louise et al. - 2011	UK
EN04 Cook, Catherine - 2012	NEW ZEALAND
EN05 Graffigna, Guendalina et al. - 2014	ITALY
EN06 Walters, Chasity Burrows - 2013	USA
EN07 Hout, Marie Claire Van et al. - 2012	IRELAND
EN08 Carlisle, Karen et al. - 2017	AUSTRALIA
EN09 Flournoy, Minnjuan W. - 2011	USA
EN10 Brooks, Fiona - 2008	UK
EN11 de Wit M, Abma T et al. - 2013	NETHERLANDS, UK
EN12 Kraemer, A. et al - 2015	USA
EN14 Hirjaba, Marina et al. - 2015	FINLAND
EN15 Maten-Speksnijder, Ada J. et al. - 2016	NETHERLANDS
EN16 Holmberg, Christine et al. - 2015	GERMANY; USA
EN17 Bailey, Kenneth Chase et al. - 2014	USA
EN18 Mitchell-Brown, Fay et al. - 2017	USA
EN19 Garcia, Jonathan et al. - 2015	USA
EN20 Pinto, Rogério M. - 2009	USA
EN21 Buck, Deborah et al. - 2014	UK
EN23 Davies, Freya et al. - 2014	NETHERLANDS, RUSSIA, NORWAY, CHINA (HONG KONG), WALES, GERMANY AND POLAND
EN24 Powell, Rhea E. et al. - 2016	USA
EN25 Robinson, Nicola et al. - 2015	UK
EN26 Abma, Tineke A. et al. - 2015	NETHERLANDS
EN28 Safo, Stella et al. - 2016	USA
EN29 Richardson, Lorilei M. et al. - 2016	USA
EN30 Cook, Erica J. et al. - 2014	UK
EN32 Hogden, Anne et al. - 2012	AUSTRALIA
EN33 McDonald, Ruth et al. - 2008	UK
EN34 Natale, Anthony P. - 2009	USA
EN35 Gien, Lan et al. - 2017	CANADA
EN36 CLOCHESY, JOHN M. et al. - 2015	USA
EN37 McCabe, Catherine et al. - 2014	IRELAND
EN38 Ross, Fiona et al. - 2014	UK
EN39 Durme, Thérèse Van et al. - 2014	BELGIUM
EN40 Rise, Marit By et al. - 2013	NORWAY

EN41 Thompson, Jill et al. - 2014	UK
EN42 Fairbrother, Peter et al. - 2013	UK
EN43 James, Delores C. S. et al. - 2017	USA
EN44 Gagnon, et al - 2014	CANADA
EN45 Young, C. et al. - 2016	AUSTRALIA
ED2 Barlow, J. H. et al. - 2009	UK
ED4 Blixen, Carol et al. - 2015	USA
ED5 Albarran, Cynthia R. et al. - 2014	USA
ED6 Burda, Marika H. F. et al. - 2012	NETHERLANDS
ED7 Hurt, Tera R. et al. - 2015	USA
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	NORWAY
ED9 Santos-Livengood, Christie A. - 2015	USA
ED10 Costello, Joanne F. - 2013	USA
ED11 Dale, Jeremy et al. - 2008	UK
ED12 Caine, Vera et al. - 2016	CANADA
ED13 Nunes, Julie A. Wright et al. - 2015	USA
ED14 Vega, Gema et al. - 2014	SPAIN
ED15 Goebbels, Adrienne F. G. et al. - 2012	NETHERLANDS
ED16 Wright, Nicola - 2013	UK
EM01 Agerskov, Hanne et al. - 2015	DENMARK
EM02 Miller, Robin Lin et al. - 2012	USA
EM03 Goldenberg, Shira M. et al. - 2016	USA
EM04 Boise, Linda et al. - 2013	USA
EM05 Oliffe, John L. et al. - 2008	UK
EM06 Phillips, Janice et al. - 2011	USA
EM07 Bhattacharya, Gauri - 2012	USA
EM08 NANTON, V. et al. - 2011	UK
EM09 Grande, Stuart W. et al. - 2013	USA
EM10 Peterson, Jennifer L. et al. - 2012	USA
EM11 Nota, Ingrid et al. - 2016	NETHERLANDS
EM12 Wiljer, David et al. - 2013	CANADA
EM13 Kowitt, Sarah D. et al. - 2015	USA
EM15 Taylor, Francesca et al. - 2016	UK
EM16 Vries, D. H. de et al. - 2016	NETHERLANDS
EM17 DiGiacomo, M. et al. - 2015	AUSTRALIA
EM18 Rivas, Carol et al. - 2012	UK
EM19 Bess, Kimberly D. et al. - 2009	USA

Quality and Ethics

The table 6 analyses the quality and ethics of the sample based on the CASP questionnaire.

Table 6 - Evaluation of quality, including ethical issues in qualitative primary research

	Statement of the aims	Appropriate methodology	Appropriate & jsutified research design	Appropriateness of the recruitment strategy	Adequate and clear description of the data collection [7]	Consideration of the relationship between participants and researchers	Explicit consideration of ethical issues[8]	Rigour of the data analysis	Clear statement of findings	Value of the research and reflection about its contribution, applicability or transferability to other populations
CO1 Sacks, A. Abt et al. - 2016	1	1	1	1	1	1	1	1	1	1
CO02 Dellasega, Cheryl et al. - 2011	1	1	1	1	1	1	1	1	1	1
CO04 Delea, Sarah et al. - 2015	1	1	1	1	1	1	1	1	1	1
CO05 Mota, Lorena et al. - 2015	1	1	1	1	1	1	1	1	1	1
CO06 Graves, K. et al. - 2011	1	1	1	1	1	1	1	1	1	
CO07 Alexander, Stewart C. et al. - 2012	1	1	1	1	1		1	1	1	1
CO08 Dowling, Joni E. - 2010	1	1	1	1	1	1	1	1	1	
CO09 Laws, M. Barton et al. - 2012	1	1	1	1	1	1	0	1	1	1
CO10 Burridge, Letitia H. et al. - 2011	1	1	1	1	1	0	1	1	1	1
CO11 Meyer, Samantha B. et al. - 2012	1	1	1	1	1	1	0	1	1	1
CO12 Rubio-Rico, Lourdes et al. - 2014	1	1	1	1	1	0	1	1	1	1
CO13 Venetis, Maria K. et al. - 2018	1	1	1	1	1	1	1	1	1	0
CO14 Hersch, Jolyn et al. - 2013	1	1	1	1	1	1	0	0	1	1
CO15 Hart, Ruth I. et al. - 2017	1	1	1	1	1	0	0	1	1	1
CO17 Garon, M. - 2012	1	1	1	1	1	0	0	1	1	1
CO19 Brez, Sharon et al. - 2009	1	1	1	1	1	0	1	1	1	0
CO20 MacDonald, Kath et al. - 2015	1	1	1	1	1	0	0	1	1	1
CO21 Berry, Judith A. - 2009	1	1	1	1	1	0	0	1	1	1
CO22 Smith, Sian K. et al. - 2008	1	1	1	1	1	0	0	1	1	1
CO23 Davies, Jane et al. - 2014	1	1	1	0	1	1	0	1	1	1

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[7] Including procedures and mechanisms

[8] sufficient details and discussion about issues raised by the study

	Statement of the aims	Appropriate methodology	Appropriate & jsutified research design	Appropriateness of the recruitment strategy	Adequate and clear description of the data collection [7]	Consideration of the relationship between participants and researchers	Explicit consideration of ethical issues[8]	Rigour of the data analysis	Clear statement of findings	Value of the research and reflection about its contribution, applicability or transferability to other populations
CO26 Wray, Ricardo J. et al. - 2009	1	1	1	0	1	0	0	1	1	1
CO27 Dolce, Maria C. - 2011	1	1	1	1	1	0	0	1	1	1
CO29 Reimann, Swantje et al. - 2010	1	1	1	1	1	0	0	1	1	1
CO31 Zulman, Donna M. et al. - 2015	1	1	1	1	1	0	0	1	1	1
CO32 Greenhalgh, Trisha et al. - 2010	1	1	1	1	1	0	0	1	1	1
CO33 Vilhauer, Ruvanee P. - 2014	1	1	1	1	1	0	0	1	1	1
CO35 Goddu, Anna P. et al. - 2015	1	1	1	1	1	0	0	1	1	1
CO36 Wilkinson, Emma et al. - 2014	1	1	1	1	1	0	0	1	0	1
CO37 Taylor, Elizabeth et al. - 2014	1	0	1	1	1	1	0	1	1	1
CO38 Duineveld, Laura A. M. et al. - 2016	1	1	1	1	1	0	0	1	1	1
ED10 Costello, Joanne F. - 2013	1	1	1	1	1	1	0	1	1	0
ED11 Dale, Jeremy et al. - 2008	1	1	1	1	1	0	0	1	1	1
ED12 Caine, Vera et al. - 2016	1	1	1	1	1	0	1	1	0	1
ED13 Nunes, Julie A. Wright et al. - 2015	1	1	1	1	1	0	0	1	1	1
ED14 Vega, Gema et al. - 2014	1	1	1	1	1	0	0	1	1	1
ED15 Goebbels, Adrienne F. G. et al. - 2012	1	1	1	1	1	0	0	1	1	1
ED16 Wright, Nicola - 2013	1	1	1	1	1	0	1	1	1	0
ED2 Barlow, J. H. et al. - 2009	1	1	1	1	1	1	1	1	1	1
ED4 Blixen, Carol et al. - 2015	1	1	1	1	1	1	1	1	1	1
ED5 Albarran, Cynthia R. et al. - 2014	1	1	1	1	1	0	1	1	1	1
ED6 Burda, Marika H. F. et al. - 2012	1	1	1	1	1	0	1	1	1	1
ED7 Hurt, Tera R. et al. - 2015	1	1	1	1	1	1	0	1	1	1
ED8 Sekse, Ragnhild Johanne Tveit et al. - 2014	1	1	1	0	1	1	1	1	1	1
ED9 Santos-Livengood, Christie A. - 2015	1	1	1	1	1	1	0	1	1	1
EM01 Agerskov, Hanne et al. - 2015	1	1	1	1	1	1	1	1	1	1
EM02 Miller, Robin Lin et al. - 2012	1	1	1	1	1	1	0	1	1	1
EM03 Goldenberg, Shira M. et al. - 2016	1	1	1	1	1	1	1	1	1	1
EM04 Boise, Linda et al. - 2013	1	1	1	1	1	1	1	1	1	1
EM05 Oliffe, John L. et al. - 2008	1	1	1	1	1	1	1	1	1	1
EM06 Phillips, Janice et al. - 2011	0	1	1	0	1	1	1	1	0	1

	Statement of the aims	Appropriate methodology	Appropriate & jsutified research design	Appropriateness of the recruitment strategy	Adequate and clear description of the data collection [7]	Consideration of the relationship between participants and researchers	Explicit consideration of ethical issues[8]	Rigour of the data analysis	Clear statement of findings	Value of the research and reflection about its contribution, applicability or transferability to other populations
EM07 Bhattacharya, Gauri - 2012	1	1	1	1	1	1	0	1	1	1
EM08 NANTON, V. et al. - 2011	1	1	1	1	1	0	1	1	1	1
EM09 Grande, Stuart W. et al. - 2013	1	1	1	1	1	1	1	1	1	0
EM10 Peterson, Jennifer L. et al. - 2012	1	1	1	0	1	1	0	1	1	1
EM11 Nota, Ingrid et al. - 2016	1	1	1	1	1	0	0	1	1	1
EM12 Wiljer, David et al. - 2013	1	1	1	1	1	0	0	1	1	1
EM13 Kowitt, Sarah D. et al. - 2015	1	1	1	1	1	1	0	1	1	0
EM15 Taylor, Francesca et al. - 2016	1	1	1	1	1	0	0	1	1	1
EM16 Vries, D. H. de et al. - 2016	1	1	1	1	1	1	0	1	1	0
EM17 DiGiacomo, M. et al. - 2015	1	1	1	1	1	0	0	1	1	1
EM18 Rivas, Carol et al. - 2012	1	1	1	1	1	0	0	1	1	1
EM19 Bess, Kimberly D. et al. - 2009	1	1	1	1	1	1	0	1	1	0
EN01 Ekundayo, Olugbemiga T. et al. - 2012	1	1	1	1	1	1	1	1	1	1
EN02 Browne, Annette J. et al. - 2012	1	1	1	1	1	1	1	1	1	1
EN03 Locock, Louise et al. - 2011	1	1	1	1	1	1	1	1	1	1
EN04 Cook, Catherine - 2012	1	1	1	1	1	1	1	1	1	1
EN05 Graffigna, Guendalina et al. - 2014	1	1	1	1	1	1	1	1	1	1
EN06 Walters, Chasity Burrows - 2013	1	1	1	1	1	0	1	1	1	1
EN07 Hout, Marie Claire Van et al. - 2012	1	1	1	1	1	0	1	1	1	1
EN08 Carlisle, Karen et al. - 2017	1	1	1	1	1	1	0	1	1	1
EN09 Flournoy, Minnjuan W. - 2011	1	1	1	1	1	1	1	1	1	0
EN10 Brooks, Fiona - 2008	1	1	1	1	1	0	1	1	1	1
EN11 de Wit M, Abma T et al. - 2013	1	1	1	1	1	1	1	1	0	1
EN12 Kraemer, A. et al - 2015	1	1	0	1	1	1	0	1	1	1
EN14 Hirjaba, Marina et al. - 2015	1	1	1	1	1	0	1	1	1	1
EN15 Maten-Speksnijder, Ada J. et al. - 2016	1	1	1	1	1	1	1	1	1	1
EN16 Holmberg, Christine et al. - 2015	1	1	1	1	1	1	0	1	1	1
EN17 Bailey, Kenneth Chase et al. - 2014	1	1	1	1	1	1	1	1	0	1
EN18 Mitchell-Brown, Fay et al. - 2017	1	1	1	1	1	1	0	1	1	1
EN19 Garcia, Jonathan et al. - 2015	1	1	1	1	1	1	0	1	1	1

	Statement of the aims	Appropriate methodology	Appropriate & jsutified research design	Appropriateness of the recruitment strategy	Adequate and clear description of the data collection [7]	Consideration of the relationship between participants and researchers	Explicit consideration of ethical issues[8]	Rigour of the data analysis	Clear statement of findings	Value of the research and reflection about its contribution, applicability or transferability to other populations
EN20 Pinto, Rogério M. - 2009	0	1	1	1	1	1	0	1	1	1
EN21 Buck, Deborah et al. - 2014	1	1	1	1	1	0	1	1	1	1
EN23 Davies, Freya et al. - 2014[9]	1	1	1	1	1	0	1	1	1	1
EN24 Powell, Rhea E. et al. - 2016	1	1	1	1	1	0	0	1	1	0
EN25 Robinson, Nicola et al. - 2015	1	1	1	1	1	0	0	1	1	1
EN26 Abma, Tineke A. et al. - 2015	1	1	1	1	1	0	0	1	1	1
EN28 Safo, Stella et al. - 2016	1	1	1	1	1	0	0	1	1	1
EN29 Richardson, Lorilei M. et al. - 2016	1	1	1	1	1	0	0	1	1	1
EN30 Cook, Erica J. et al. - 2014	1	1	1	1	1	0	1	1	1	0
EN32 Hogden, Anne et al. - 2012	1	1	1	1	1	0	0	1	1	1
EN33 McDonald, Ruth et al. - 2008	1	1	1	1	1	0	0	1	1	1
EN34 Natale, Anthony P. - 2009	1	1	1	1	1	0	0	1	1	1
EN35 Gien, Lan et al. - 2017	1	1	1	1	1	0	0	1	1	1
EN36 CLOCHESY, JOHN M. et al. - 2015	1	1	1	1	1	0	0	1	1	1
EN37 McCabe, Catherine et al. - 2014	1	1	1	1	1	0	0	1	1	1
EN38 Ross, Fiona et al. - 2014	1	1	1	1	1	0	0	1	1	1
EN39 Durme, Thérèse Van et al. - 2014	1	1	1	1	1	0	0	1	1	1
EN40 Rise, Marit By et al. - 2013	1	1	1	1	1	0	0	1	1	1
EN41 Thompson, Jill et al. - 2014	1	1	1	1	1	0	0	1	1	1
EN42 Fairbrother, Peter et al. - 2013	1	1	1	1	1	0	0	1	1	1
EN43 James, Delores C. S. et al. - 2017	1	1	1	1	1	0	0	1	1	1
EN44 Gagnon, et al - 2014	1	1	1	1	1	0	0	1	1	1
EN45 Young, C. et al. - 2016	1	1	1	1	1	0	0	1	1	1

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Disclosure statement

No potential competing interest **is** reported by the authors.

Ethical statement

This research is a review article and does not involve human and/or animal subjects. The study was conducted ethically and responsibly in full compliance with the eligible standards of integrity and relevance of the research and, specifically, review works, acknowledgement of all primary sources consulted and revised.

Data availability statement

The tables with excerpts and verbatim quotations extracted from studies sampled are available as complementary materials in the Annexes and also deposited on the Institutional Repository of the University of Valencia Roderic (roderic.uv.es) at https://hdl.handle.net/10550/80264

ANALYSIS AND RESULTS

Enhancing the impact of interventions in chronic health: a transnational qualitative meta-study on sampling, recruiting and communication with vulnerable populations

One-hundred-three (103) papers matching the inclusion criteria were identified, selected and analysed. The papers were related to:

- Communication and counselling: this theme covers the enhancers, facilitators, barriers and challenges of the communication between clinicians (HCPs) and patients, mainly within the counselling context
- Health literacy: it covers the informal education conducted by the patients, by themselves and through their interaction with the immediate environment, as well as their participation in non-formal health education and health literacy programmes and their involvement in mutual support groups.
- Adherence, compliance, self-management and decision-making: this theme reflects, progressively, the themes concerning adherence and compliance (from more passive to a more proactive role), self-management of a chronic condition (active engagement in self-care) and decision-making about treatments, care pathway and one's health challenges (critical and active engagement).
- Empowerment: the last theme is focused on communities in particular vulnerability situations, their empowerment and its relation with the individuals' autonomy, self-efficacy and capacity for making decisions
- The role of the IT tools and the Internet analyses the role of technologies in communication, access to information and health literacy, self-management and, ultimately, the autonomy of patients and communities; this theme was extracted from the theme on self-management due to its transversal nature and particular relevance when addressing barriers and enablers with more vulnerable communities and persons.

Also, two analytic themes were used for classifying the information: **facilitators** and **barriers**. Sometimes, in parallel, **advantages** or **disadvantages** were utilised.

In addition, the constructed items were classified in factors linked to *socio-ecological model; thus:*

- **Microlevel factors** join intrapersonal and interpersonal factors related to the themes and challenges above described
- **Mesolevel factors** refer to the communities and their values and culture/cultural norms (if these are not congruent with the hegemonic culture and Ideology), as well as the organisational particularities (e.g., those

healthcare and social work facilities in touch with the communities, research institutions involved with the communities or patients, etc.)
- **Macrolevel factors**, referring to policies, politics, structural and systemic determinants.

Each item contained in these categories was re-interpreted and summarised to capture the key idea behind the statements analysed to make them operative for constructing middle-range theories (full quotations are shown in the complementary materials).

Section 1. Counselling and communication: factors and co-determinants in communication and counselling

This section analyses the factors involved in the counselling and healthcare professionals' consultation with patients. The quotations codified were analytically divided into barriers and facilitators; each analytic theme is, at the same time, subdivided into dimensions, accordingly to the socio-ecological model: micro- level (intra and inter personal), meso-level (settings, culture, groups) and macro-level (policies and systems)

Microlevel determinants in the counselling: intrapersonal and interpersonal factors

The microlevel is divided into intrapersonal and interpersonal. The intrapersonal level refers to internal statuses, beliefs, determinants or any other factor intrinsically internal to each individual (patients, providers, etc.), and the interpersonal level refers to the relational factor, while founded into the intrapersonal dimension.

Intrapersonal

At the intrapersonal level, it should be differentiated between **communication skills** - that can be acquired and modified - and the **individuals' internal aspects** (concerning the relational aspects further detailed in the next section on the Micro-level inter-personal factors).

Firstly, the health care professionals' skills -and how these are perceived and assessed by patients - are critical and, in particular:

- the clarity (the extent to which the explanations are giving understandably and straightforwardly)
- the directness (thus, to communicate without hedging or detours)

Both directness and clarity are linked: it would not be possible to communicate without hedging and without adapting the terms used and the type of interaction. On the contrary, patients may report disappointment, intimidation, humiliation or be overwhelmed by an inappropriate amount of information.

Secondly, communication styles and processes to deliver information and trust experienced by the individual are considered, as long as these found the inter-personal dimension in the act of communicating during the counselling. Linked with the previous skills, to provide enough information meeting the patient's information demands, attending to side-effects, prognosis and expectancies are key: to give full, complete and detailed information is valued by patients as well. Pragmatic advice (e.g., suggestions focused on coping or wellbeing) and balanced information provision is essential too.

Lastly, concerning the intrapersonal level, trust refers to the individuals' perception of being in a safe environment: private, peaceful and, in broad terms, trustable.

Concerning the co-determinants involved, literacy, self-efficacy, age, physical and cognitive functions impact on all these factors.

Table 6 - Counselling and communication: Facilitators and barriers at the intrapersonal level

Facilitators	Barriers
Individual HCPs' skills and the patients' perception - Clarity (CO09, CO11, EN06, EN14, EN23, EN36, EN38, EM01 - Directness (CO09, EN06, EN14, EM01) - To inform on time, respect the patients' pace (EN32, EN40) - To check the understanding (CO07, CO09) - Generalising the condition instead of personalising (CO13) - Impersonal information provision (CO13) - Brochures (EN09)	Co-determinants - Lower literacy (CO14, CO22, EN45) - lower self-efficacy (CO14, CO22) - Age and/or physical and cognitive functions (CO36)
Individual dimension of the relational aspects	
Communication style - HCP o Affectionate styles (CO1, CO02, CO06, CO08, CO10, CO21, CO29, EN02, EN36, EN38, ED14) o empathy (CO21, CO29, EN19, EN36, ED14) o Awareness of power differentials (CO29, EN02, EN07, EN09, EN19, EM17) o non-verbal communication (EN02) - Patient o To feel heard (CO1, CO02, CO06, CO08, CO10, CO21, CO29, EN02, EN36, EN38, ED14) o to feel cared (CO1, EN36, EN02) Information delivery - Providing enough information (CO06 CO07 CO08 CO09 CO10, CO11, CO13 CO14 CO23, EN01 EN02 EN07, EN14 EN23, EN32, EN38 ED8, EM11 EM12) - Information demands met; all needed info is available (CO01, CO14, CO29, CO31, EN02, EN03, EN14) - updated knowledge of the HCP and the evidence-based information (CO33, CO31, CO13) - Information about consequences, side effects and prognosis (CO04, CO06, CO07, CO08, CO10, CO11, CO13, CO14, CO15, CO29, CO31, CO32, EN01, EN02, EN09, EN15, EN38, EN40, EM12) - Mode or style - Detailed explanations; go to details (CO01, CO06, CO08, CO11, CO13, EN15, EN38) - Full, complete (CO14, CO31, CO33, EN06, EN09, EN15, EN38) - Pragmatic o Suggestions (CO07, CO08, CO21, CO29, CO31, CO32, CO35, CO36, EN01, EN03, EN09, EN16, EN36, EN40)	Patients' adverse perceptions: - Disappointed o Poor interpersonal communication (CO01, CO09, CO04, CO10, CO20, CO23, CO29, CO29, EN01, EN05, EN09, EN14, EN15, EN38, EM04, EM08, EM11, EM17) o lack of connection between the information perceived and the patients' own universe of meanings (CO04, CO06, CO19, CO23, EM01, EM04, EM07) o poor informational support (CO11, CO20, CO23 CO27, EN38, EM04) o failed expectations related to evidence-based practice (CO06, CO09, CO23, CO27, CO31, EN01, EN35, EN39) o overestimated clinical expertise, very high expectations (CO23, EM04) - intimidated (CO01, CO04, CO9, CO20, CO21, CO23, CO29, EN01, EN04, EN05, EN06, EN36, EM01 EM08, EM11, EM17) o Negative reactions by the HCP to the disclose of info (EN06, EN33) - Humiliated (CO01, CO04, CO09, CO23, EN04, EN36, EN38, EM07, EM08, EM17)

▪ Wellbeing; extended life (CO07, CO32, EN03) ▪ Coping strategies; emotional support & self-management resources/strategies (EN03, CO32) ▪ accompanied of additional resources (CO31, EN01, CO08, EN09) ▪ coordinated with patient associations and support group (CO01, CO08 CO27) ▪ accompanied of info about health services (EN01) o Instructions (CO21, CO07, CO29, EN05, EN06, EN16) ▪ Curative goals (CO07) ▪ Side-effects (CO29) o Opinions ▪ Giving explicit opinions (CO21,CO36) o quotidian-life related; relevant for the everyday life (CO32, EN01, EN15) o Interactive (CO09, CO11, EN40) - Balanced (CO01, CO06, CO08, CO14, CO29, EN06, EN15) o adapted to the level of understanding, comprehension and literacy (CO01, CO06, CO08) o appropriate amount of information (CO14, EN06) o simple language, plain and simple explanations (CO01) o understandable (CO29, CO31, EN09) - Gradually (CO01, CO07, CO14) - accompanied by reassurance (EN03) - Use of shock tactics (EN08, EN34) o Statistics (EN34) Trust - safety o safe; private, peaceful, safe environments (CO08, EN19, EN02, EN14, EN36, EN38, ED12) o HCPs; of the interaction (CO11, CO29, EN02, EN36, EM11) o Information exchange (CO06, CO35, EN14, EN36) o Tests, screening; early detection (CO06, CO29, EN01) o personal safety (EN02, EN36, EM12) o peers (CO26, EM09) o Privacy (CO29, EN36) o Diagnosis (CO29) - Given or gained: o 'gained'; it is not given or implicit(CO06, CO11, EN02, EN12, E EN14 N23, EN36) o Given, implicit (EM11) - dependent on the reactions of HCPs (CO11, CO29, EN36 EM11, EM12) - bidirectionally established (CO35, EN14, EN23, EN26, EN36, EM11) o comfortable (EN36, EM11) o continuity of care (EN23) o all-along the way (EN26)	o Stigmatised (EM08, EN33, EN38) o Labelled (EN33) - Overwhelmed by o unclear terms, technical jargon and specialised terms (CO01 ,CO8, CO14, CO22, CO23, CO31, CO36, EN45, EN24, EM11) o amount of information (CO1, CO14, CO22, CO36, EN24, EM11, CO31, EN24) o the HCPs' impersonal style (EN15, EN45) o the inappropriate timing of the information delivery (CO36, EN24) ~~o~~ heavy assessment and evaluation (CO13, CO31) - infantilized; treated "like a child" (CO02, CO09, EN33, EM04, EN40) o Overruled (CO02, EN33, EN40) - Stressful (CO02, CO08, EN05, EN33) o lack of desire for information (CO06) - Angry (CO08, EN05, EN18, EN38) - Powerlessness, helplessness (EN04, EN10, EM01, EM17) - Frustrated: o Skill-related/expertise issues ▪ the lack of info causes frustration (CO01, CO04, CO08, CO13, CO19, CO20, CO23, CO36, EN35, EN39, ED8, ED9, ED13, EM01) ▪ simplicity (CO13, CO15, CO22, EN01, EN05, EN35, EN39, ED8), ▪ Lack of HCPs' expertise (CO06, CO09, CO11, CO27, CO38, EN20, EN38, EM04) ▪ The HCP seems to be retaining information (CO36) ▪ HCPs refusal to accept culpability (EN33)

- allowing the patient to ask (CO07, CO08, CO09, CO29, CO36, EN03, EN09, EN36, EN40, EM01, EM11) dependent on the reactions of peer groups (CO26, EN12, EM09) - diligence; expertise (CO29, EM11) - transparency (EN09) - sincerity (EN14) - reliability o HCPs recognise their own limitations by referring the patient to another specialist more experienced or trained in a particular problem (CO29, EN06) o The HCPs' hypothesis is confirmed (CO29) o HCPs admit their vulnerability (EN02, ED19, ED10) o trust in the command/mastery of the HCP (CO01, CO08).	

Inter-personal

Interpersonal dimensions at micro-level refer to all factors involved in the relations between a small number of individuals founded on its intrapersonal characteristics; however, the meso and macro-level are also involved in every human interaction. In this context, the interpersonal dimension in the counselling design all communication circumstances, challenges, issues and favourable characteristics between healthcare professionals and patients.

Firstly, the **therapeutic relationships'** characteristics are critical; the therapeutic relationship depends on both parties: patient and HCP. Therapeutic relationships need to balance power and consider the rapport-building factors (listening, warmth, mutual trust, security and others detailed in the table) to build partnerships between parties and improve the person's wellbeing. Mutual respect is also involved: patients may respect HCPs due to their knowledge or expertise, the information sharing process or the social competencies showed; even patients can feel that they have a duty to respect HCPs. The HCP respects patients recognising and validating their experience; they usually feel respected if the patient is honest and highly involved or implicated in their own self-care or self-management. Patients' and HCPs' relational issues arise as well: mixed feelings and perceptions may appear on the patients' side (perceives to receive poor attention, avoidance, feels infantilised, angry, confused, among others). HCPs styles and attitudes play a major role, too: confrontational and directive styles, impersonal style, or paternalism may undermine the therapeutic relationships. In addition, specific problems in the information delivery (unclear information or not sufficient data about prognosis, side effects, duration and any other informational needs) also appeared.

Secondly, **counselling** is related to decision-making, and both themes are usually inter-linked: counselling supports decision-making and joint decisions, but specific challenges may appear in the information delivery: again, it may be insufficient for the patient, mediated by time constraints, inappropriate considering the patients' literacy or knowledge or not sufficiently focused. Also, cultural paradigms are a complex field in counselling: HCPs and patients may have unshared cultural values and worldviews that might suppose a poor integration between the advice, the lexicon and language used and the quotidian experience of the patient; some sensitive topics are sex, end-of-life or LMIC's diseases.

Table 7 - Counselling and communication: Facilitators and barriers at the interpersonal level

Facilitators	**Barriers**
Interpersonal dimension of the relational aspects	
▪ **Good therapeutic relation** (CO01, CO02, CO04, CO06, CO07, CO08, CO09, CO10, CO15 CO19, CO20, CO21, C029, CO32 CO33, CO36, CO38, EN01, EN02, EN05 EN09, EN10, EN14, EN16, EN32, EN38, ED4, ED5, ED8, EM11, EM12) • Balancing power in the therapeutic relationship ○ relationship focused on the person empowerment – autonomy (CO06, CO10, CO29, EN36, EN38) ○ Raising the empowerment – autonomy of patients (CO02, CO06, CO06, CO37, EN06, EN09, EM11) ○ Let people decide (CO08 CO27 CO37 EN09 EM08 EM11) • Rapport building qualities ○ listening (CO01, CO02, CO06, CO07, CO08, CO27, CO38, EN09, EN14, EN36, EN38, ED14, EM01, EM12, EM17) ○ warmth (CO01, CO07, CO10, CO20, CO27, CO36, CO38, EN05, EN06, EN10, EN15, EM17) ○ trust (CO01,CO06, CO08, CO10, CO15, CO20, CO23, CO27, EN38, ED5, ED14, EM01, EM17) ○ security (CO01, CO02, CO06, CO07, CO08, CO10, CO27 EM01 EM17) ○ Reassurance (CO02, CO04, CO13, CO27, CO38, EN05, EN09, EN16, EN36, EN38) ○ Friendliness (CO01, CO09, CO37 CO27 CO29, EN09 EN15 ED5, ED14) ○ non-judgmental (CO02, CO06, EN02 EN07 EN09 EN15 EN38) ○ dialogue (CO01, CO14, CO19 CO38 EN05 EN38) ○ Empathy (CO01, CO04 CO27 EN14 EN15) ○ proximity (CO01, CO09, CO32, EN02, EN05) ○ Encouragement (CO02 EN14 EN15 ED4 ED5) ○ Kindness (CO01, CO04, CO09, CO27)	Patients' Relational issues - Perceived issues with the relationship with the HCP ○ poor attention to the psychological aspects (CO01, CO02, CO06, CO07, CO08, CO10, CO20, ED08) ○ Insufficient attention received (CO10, CO11, EN15, EN36, ED13, EM12) ○ infantilized; treated "like a child" (CO02, C008, CO09, CO13, EN23, EN33, EM04, EN40, ED9) ○ Overruled (CO02, EN33, EN40) ○ **Inappropriate knowledge acquired (EN35, ED9)** ○ **Specific issues in the HCPs communication skills:** ▪ **The HCP is too soft (CO20)** ▪ **The HCP is hedging (CO07)** - Angry (CO08, EN05, EN18, EN38) - **Afraid of results (CO06)** - Confused (CO09CO14, CO31, EN01, EN15) - The patient is frustrated because of telling the same story over and over (CO20)
	HCPs'styles: - Confrontational and directive styles ○ Confrontational and directive communication (CO02, CO01, CO09, CO21, CO36, EN14, EN33, EM17) ○ Showing antagonism (CO21, CO36, EN10, EN33) ○ Accusing; guilt-provoking (CO01, CO02, CO09, EN14, EN33) ○ Being disrespectful; mocking (EN33, EM08) ○ Showing tension (CO21, EN10) ○ HCP defensiveness (EN10) - Impersonal style ○ Impersonal communication (CO3, EN06, EM06)

o Non-verbal cues (CO10, CO37, EN02, EN35) o Cordiality (CO01, CO07 CO37) o commitment (CO01 CO27 CO32) o dedication (CO01 CO38 EN03) o support (CO01 EN16) o company (CO01 EN16) o acceptance; positive regard (EN02 EN07, ED14) o being attentive (CO01 EN38) o professionalism (CO23 CO27) o recognising and remembering the patient (CO01 EN09) o Anticipation (CO10, CO15) o Motivating (CO02 EM11) o Chit-chat (CO37) o Affection (CO01) o discretion (CO01) o sensitivity (CO01) o sympathy (CO01) o good humour (CO01) o tranquillity (CO01) o tact (CO01) o determined (ED5) - partnership (CO21, EN38) - improving wellbeing (EN38) - Emotional support o Paying attention to psycho-emotional factors (CO01, CO02, CO06, CO08, CO10, CO28, CO38, EN02, EN19, EN24, EN36) o open questions about the general circumstances of the patient (e.g., "How are you") (CO01, EN15) Further exploration of experiences reported by patients (CO01) Respect - The patient respects the HCP o Information (CO01, EN14) o by acknowledging the expertise, rigour, knowledge or prestige (CO01, CO08, CO09, EN09, EM11) ▪ professionalism (CO01, CO09, EN40, EM11) ▪ prestigious institution (CO01) ▪ reputation (CO01, CO08, EM11) ▪ accuracy in diagnosing (CO09) ▪ trained (CO01, CO09) o relational/social competencies ▪ the patient observes that the HCP respects others (CO08) ▪ transparency (CO09, EN14) ▪ trust (EN14) ▪ the HCP seeks the patient feedback (CO08) ▪ Warmth and friendliness (EN09, EN40, EM12) ▪ The patient feels heard and seem (EN40) o The patient feels a duty to respect (EN14) - The patient feels respected by the HCP (CO20 CO23 EN02 EN07 EN09) - The HCP respects the patient	o Focus on the disease instead of the patient (CO20, CO36, EN15, EN24, EM06) - Paternalism (CO02, CO13, EN10, EN32, EN33, EM17) o Preventing patients' for looking info on the Internet) (CO08, EN32) o Limiting the access to self-management resources to the most capable (EN23) **HCPs'Attitudes** - Unreceptiveness (CO10, CO20, CO27. CO36, EM06, EM11) - Dismissing the patients' view (CO04, CO08 CO20, CO27, EN10, EM11, EM17, CO27, ED9) - Denying or hedging to discuss treatment options (CO27, EM06) - Monologues, repetitive (CO09, CO20) - Labelling, e.g., "difficult patients" (CO19, EN10, EM17, EN33) - Rude (CO29, EN09, EM08) - Arrogant (CO29, EN01) - Unfriendly (EN01, EN09) - Incongruence between body and verbal messages (EN06) **HCPs'problems in providing/exchanging information** • **Unclarity, general** (CO01, CO03, CO04, CO08, CO09, CO14, CO15, CO23, CO27 CO31 CO36, CO38, EN01, EN05, EN21, EN35, EN39, ED08, ED8, ED9, ED13, ED14, EM01, EM08, EM11, EM12, EM17) • Lack of clear **medical/health/treatments information** o the prognosis (CO01, CO04, CO07, CO08, CO36, EN01, EN05, ED14, EN39, ED8, EM08) o side effects (CO01, CO08, CO09, CO14, CO31, EM08) o duration of the treatment (CO01, CO04, CO31, ED8, EM08) o reliability of procedures and tests (CO14, CO22, CO27) o relapses (CO01, CO08) o meds interactions (CO31) o diet (EN35) o risk/harm reduction (ED9) o causes (ED14) o aids and supports (EM08)

o To recognise the patient provided information (EN40, EM12) o To recognise the value of the culture and spirituality of CALD (CO06) o To hear the patient (EN40) o To value the patient (EN40, EM12) - The HCP feels respected o Honest patients (EN14) o high implication of patients as a self-evident value in all treatments (EN40 EM12) o	
Decision-making: support, availability, shared - Open communication (CO06, CO07, CO15 CO21 CO27 EN02 EN03 EN36 EM11 EM12) - To empower patients (foster the sense of agency) o To allow them to make realistic and autonomous decisions (CO02, EN01, EN03, EN26 EN38, EN38, EM11). ▪ In control (EN38, EM11) ▪ Positive (EN38) o To share decision-making (EM11) o To set their own agenda/goals (CO02, EN26, EN38, EM11) o To support/promote the use of mutual support groups, health literacy programmes or the participation in patients' associations (CO26) (CO08 CO27 EN02 EN40)	**Specific problems of the information delivery:** o Insufficient (CO01, CO04, CO07, CO08, CO13, CO15, CO23, CO27, CO36, CO38, EN05, EM01, EM08) ▪ vague, fuzzy (CO07, CO15, CO38, EN01, EN05, EN35, EM08, EM11) ▪ jargon (EN01, EN21, EM11) ▪ abstract rules (EN05, EN35) o Time constraints (CO01, CO02, CO19, EN05, EN23, EN35, EN36, EM08, EM11, EM12) o Inappropriate for their previous level of health literacy (CO22, CO23, EM11) ▪ potentially sub-optimal health numeracy ignored by providers (CO22, CO23, ED13) o not focused on the specific problem/disease (CO15, EM11) o Dialectical conflict between professionals' treats and caring roles (EN23, EN33) o too late (CO03) o unstructured (EM01) o Poor quality of the translation (CO12) o Failing in asking open questions (CO09) o **culturally complex themes** ▪ overlooked differing cultural paradigm (CO12, CO23, CO37, CO37, EN18, EM04, EM17) ▪ poor integration between the medical advice, the lexicon and language used and the daily life of patients and communities (CO23, EN05, EN18, EM08, EM17) ▪ sex (CO12, CO23, ED8, ED9, EM08) ▪ graphic design and cultural representations (CO22) ▪ death and end-of-life issues (CO07) ▪ refusal of children to translate some subjects (CO12) ▪ Unfamiliarity with LMIC's illnesses (EM04)
	Co-determinants - With CALD persons/communities, accurate estimation of the mutual understanding (CO23) - To avoid asking for **making massive decisions** but lacking info (CO08, EN39, EM11) (CO01, CO31, EN15) - potentially **sub-optimal health numeracy** ignored or well-assessed by providers (CO22, CO23, ED13)

Meso-level determinants in the counselling: settings, culture and values

At meso-level, in regards to settings and culture of the communities, two sub-dimensions can be differentiated: organisations (e.g., clinics, hospitals, primary attention centres, etc.) and communities' values and customs.

Concerning **organisational settings**, the time available seems to be the most important barrier and facilitator, including human resources and resources and budget. These factors play a role in the availability of HCPs, nurses' role, the quality management procedures in each organisation and, even the information about cultural differences and epidemiological realities in the country of origin of CALD - including migrants. Co-determinants referring to organisations are the continuity of care, including the follow-up process and case management, and the system's complexity.

Regarding the **communities’ values and customs**, a complex network of inter-personal and moral issues act. Inter-personal aspects are relevant to communities' values. They could severely impact patients' lives: the need to consider the social and historical factors that may be involved in the counselling, or the presence of survivors' groups and peer-supported networks or initiatives are present in the patients-providers communication.

Values are also critical. On the one hand, feeling useful and providing care, even the sense of courage, repeatedly appeared as a facilitator in the counselling - being culturally mediated. Interestingly, participation in health education programmes also appeared linked to the counselling and the role that feeling useful has for them: the community spirit, empowerment, and community involvement are related to the previously mentioned inter-personal factors. On the other hand, the authoritarian or paternalistic styles are a barrier for counselling, particularly with counter-hegemonic groups and discriminated communities.

Lastly, **culturally-tailored communication** emerges again, concerning the mutual and sharing understanding of key information transferred and the comprehension of communities' needs. The role of relatives, the importance of punctuality or the similarity between providers and patients (e.g., ethnically similar, same gender, etc.) also appeared as sociocultural-mediated factors facilitating communication.

Co-determinants at the meso level are part of a CALD community and the stigma that the patient or patients may suffer.

Table 7 - Counselling and communication: Facilitators and barriers at meso-level

Facilitators	Barriers
Organisational settings	

- Time (CO01, CO02, CO08, CO10, CO19, CO27, CO29, CO33, EN03, EN36, EN38, EM12) - Continuity of care and the internal coordination of professionals (CO1, CO08, CO32, EN02, EN05, EN09, EN15, EN16, EN38) o regular follow-up (CO08, EN02, EN05, EN15) - Availability of the HCPs (CO1, CO06, CO08, CO09, CO19, CO27, CO29, CO31, EN05, EN16) - Nurses role (CO01, CO02, CO20, CO36, EN06, EN15, EM17) - to seek for patients' feedback in regards the quality evaluation (CO08, CO29, EN09) - brief waiting periods (CO29, EN02) - CALD communities o Information about the diseases in origin (CO05) o Consideration of the cultural differences (CO05)	- Time-constraints; rushed (CO02, CO04, CO08, CO09, CO10, CO20, CO23, CO29, EN06, EM17) - Time consuming (CO20, CO29, EN05) - budget/resources consuming (EN18, EM04)
Co-determinants - **continuity of care** (CO23)	Co-determinants - **Complex system**, difficult to navigate (CO31, CO32, EN24, EN38, EM17) - Needed **follow-up** during the treatment and the transition (CO01, CO08, CO10, CO11, CO23)
Communities, culture and values	
Interpersonal aspects and links with the community and the role in citizenship - Consideration of the socio-historical factors during the counselling (CO06, EN19, EM09) - Presence of networks of survivors, peer-support (CO08, EN19) - Opportunities for socialising (EN19) - Fighting stigma and marginalisation (EN19) - To pay attention to carers (CO10)	- Authoritarian and paternalistic approaches ((CO02, CO01, CO09, CO13, CO21, CO36, EN10, EN14, EN32, EN33, EM17)
Values - To feel useful ▪ HCPs would find themselves "useful" for patients by - providing care, general (CO05, CO06, EN33, ED11) - paying attention to psycho-emotional factors (CO06, CO10, CO20, CO21, EN15, EN33, EM19) - Fostering the motivation for providing care for complex patients (CO05)(CO06) o to enjoy the challenge that those complexities present (CO05) ▪ HCPs perceptions - a sense of courage and involvement in the patients' agendas (CO17, CO20 , EN15 EN25, EN33, EN41) - raising awareness and fostering the advocacy of patients (CO17. EN25, EN41) - greater sense of credibility (EN15, EN25, ED11) ▪ Patients feeling useful - motivation for participating in peer-based programmes and research programmes (EN03, EN07, EN21 EN25, EN28, EN45, ED5, ED8, ED10, ED11, ED16, EM05, EM10, EM11 - empowerment (CO06, EN21, ED5, EM05)	

- community spirit (EN03, EN21, EN28, EN45, ED5, ED8, ED10, EM05) - moral duty (CO10, EN03, EN21, ED5, ED7) ○ religious (ED5) ○ family (CO10, EN03, ED7) - empathy (EN07, ED16, EM10) - valuable information (CO06, EN45, EM05) - raising public awareness (EM05) - CALD culturally appropriate contextual translation to allow a shared understanding of the important information (CO23, EN35, EM17) - Outreach the communities' specific needs (EN24, EN35, EM17) - Face to face encounters (CO32, EN30, EM17) - to inform relatives and to know them (EN32, EN36) - punctuality (CO29) - Similarity HCP-Patient – e.g., ethnicity (EN30)	
○	Co-determinants: - CALD (CO12, CO23, CO37, CO37, EN05, EN18, EM04,EM08, EM17) - Stigma (EM08, EN33, EN38) - Material deprivation - Lower education - Difficulties in addressing death and end-of-life issues (CO07)

Macro-level determinants in the counselling: policies and systems

Macro-level refer to policies and structural determinants, including the healthcare or social care systems and procedures; however, macro-level circumstances are directly related and involved by and through meso-level and sociocultural issues.

The most critical facilitator resulted in person-centred care and the trauma and violence informed care; integrated, comprehensive systems and continuity of care (guaranteed by public policies rather than organisational particularities) also appeared, jointly to easy access and navigation to care systems in place. Some barriers should be considered as well: the frequency and direct care received by patients with chronic diseases are fewer when compared with acute illnesses, the training of the HCPs need to be more comprehensive and, among other things previously explained, include and consider how the social, economic and cultural inequalities impact on health disparities.

Table 8 - Counselling and communication: Facilitators and barriers at macro-level

Facilitators	Barriers
- person-centred care (CO01, CO02, CO08, CO29, CO33, EN02, EN16, EN24, EN36, ED14, EN32, EN36, EN40) - Integrated comprehensive care (CO08, EN38) - Continuity of care (CO1, EN38) - Trauma and violence-informed care (EN02, EN07, EN19, EM17) ○ Collective development of new discourses in Public Health avoiding the reproduction of stigma (EN19) - Easy access/navigation to care (EN38)	- chronic diseases may receive less **frequency and direct care** than acute conditions (EM17) - Needed more **training for HCPs** (EN20) - Consideration of the social determinants of health

Section 2. Health literacy

This section is divided into three big themes: i) **self-directed health-literacy** – thus, informal learning about medicine and health; ii) the **recruitment** of persons for health promotion and health education programmes; and iii) the facilitators and barriers for **implementing and conducting** health education programmes, including the recommendations for engaging persons and retaining participants.

All these themes are, at the same time, subdivided in-line with the socioecological model: Micro-level (intra and interpersonal dimension); meso-level (settings, environment, culture and values) and macro-level (policies and structural conditions).

Individual health literacy: self-directed health education

Health literacy "represents the cognitive and social skills that determine individuals' motivation and ability to gain access to understand and use information in ways that promote and maintain good health" as defined by Nutbeam, cited by (Edwards, Davies, and Edwards 2009). Health literacy can be acquired through self-directed education or, in other words, informal education; it means autonomous access, selection and evaluation of the information sources used for increasing the individuals' knowledge, skills and decision-making capabilities.

Micro-level determinants of health literacy

Facilitators and barriers are reviewed at intrapersonal and interpersonal levels; the studies reviewed highlighted a link between health literacy and capacity for decision-making; thus, the lack of information interferes with the ability for making decisions. Isolation, lack of social network and support and access to incomplete or non-accurate information, or tricky, unclear data are barriers to health literacy. Also, to perceive that the HCP is retaining knowledge or to perceive a lack of data about side effects acts as a risk for increasing health literacy. At the interpersonal level, the most important sources of knowledge - thus, facilitators of health literacy - are friends, families and specialists; also, education programmes and peer-based groups appeared. The expectations and preferences of persons may also facilitate the acquisition of health self-directed education: to expect more informational speech from providers appears to be a facilitator; simplified but still rigorous information, direct, short if needed, considering the special demands of some patients (cancer, youngsters, patients with HIV or multiple chronic comorbidities or MCC). To put in place means and resources for CALD persons (interpreters, visual aids, etc.) also facilitate health literacy acquisition.

Table 8 – Health literacy: Facilitators and barriers at micro-level (intra and interpersonal)

Facilitators	Barriers
Intrapersonal factors	
Constructs (conversely to facilitators) • Higher literacy/education • Higher self-efficacy • Better access to information	**Patients** • The lack of information interferes with the decision-making (CO01, CO08, CO14) • isolation and lack of social networks (EM04) • the information is not complete and accurate (CO06, CO14, CO22, CO26, CO31, ED9, EM17, EN32, EN39, EN45) • The patient perceives that HCPs retain information (CO01, CO15,EM12, EN39) • misunderstood information (CO06, CO22, EM17) • their psychological- emotional demands are not met (CO06, CO14, EN45) • tricky (CO31) • unclear (EN05) • lack of data about side-effects (CO08 **HCPs** • paternalism; patients discouraged for looking for more information on others means (CO08, EN32) • lack of expertise (CO27) • the information is not well adapted (CO22)
Interpersonal factors	

Sources of knowledge:
• **Friends** (CO01, CO12, ED09, EN35)
• **Family** (CO35, ED9*, EN35)
• Second opinion; **Specialists** and experts (CO06, CO08, CO27, EN01)
• Interpersonal and relational interaction; socialising
  ○ Peer-based groups (CO08, CO27, CO29, CO32, CO35, EM10, EM15, EN04, EN08, EN34)
    ▪ Online support groups (CO27, EN04)
  ○ **patients' education programmes** (CO23, CO29, EN01, EN25)
    ▪ **with experts** (ED6)
Expectancies; preferences
• high degrees of informational **speech** from their provider (CO08, CO13, C019, CO27, EM12
• **simplified** (CO01, CO22, CO29, EN05)
• Special demands
  ○ Oncologic patients (CO01, CO08, CO27, EM06)
  ○ Youngsters (EM06)
  ○ HIV (EN34)
  ○ MCC (CO29)
• CALD
  ○ interpreters and culturally tailored concepts (CO23, EM17)
  ○ Preference for visual aids and graphic information (CO23)
  ○ Story telling may work fine too (CO22, CO23)
  ○ Information should be delivered in the native language (CO23)
  ○ Alternative programmes can be designed specifically for non-native speakers (CO36)
	Micro-level - Interpersonal
	• Weak associations (EN39)
	Constructs (conversely to facilitators)
	• Lack of social support
	• Lack of health education programmes available
	• Preference for low degrees of informational speech

○ Help would be needed for navigating the healthcare system (EN24) ○ Check for understanding (CO23) ○ Locally (CO36) • to feel guided (EN05) • **direct** and **short** (CO22) • **updated** (CO19)	

Meso-level determinants of health literacy

At the meso-level, organisational and community settings should be both considered. The complexity of the healthcare logistics and the access to health care appears as a barrier for enhancing the persons' health literacy at the organisational level. At the community level, values and culture level, the interaction of informal education (thus, self-directed health literacy) with the individuals' culture is the most important factor, including the access to the Internet and mass media and the means used for acquiring knowledge. The existence of community places for exchanging knowledge and experience is a significant facilitator as well. In regards to barriers, gender and racialisation should be considered. How the sexual taboos and cultural factors may undermine the access to information, and the transparent exchange of knowledge, the ways for socialising and the racial disparities in health and education must be taken into account.

Table 9 - Health literacy: Facilitators and barriers at micro-level (intra and interpersonal)

Facilitators	Barriers
Organisations	
Constructs (conversely): - Integrated and simple to navigate systems or healthcare logistics	Healthcare logistics are **complex** (EM04, EN24)
Communities, values and culture	
Sources of knowledge: • **Individual interacting with culture; informal education** ○ **Internet** (CO01, CO08, CO27, ED09, EM08, EN05, EN37) ○ Mass media (CO26, EM08) ○ DVDs or videos (EN01) ○ books (EM08, EN37) ▪ **Formats:** • brochures (CO04, CO29, ED5) • **websites** providing reliable and evidence-based information (CO08, CO22, CO31) • Mobile apps (CO31, CO32) • graphics, charts, pictures and visual formats (CO04, EN34) • written information (CO29) • not-written (CO22) • **community places** ○ Associations (CO01, CO26, CO32) ○ fraternal organisations (CO26, EN08, EN35)	Culturally-based inequalities and social determinants of health • gender issues ○ masculinity and prostate cancer screening (CO26) and treatment (EM08) ○ femininity, ethnicity and age and how it supposes a problem in the HC system (EM17) • racialisation ○ the disparity in health information access (EN01) Constructs (conversely): - Low or no access to Internet - Poor adaptation of informative materials and health literacy resources - Lack of community places and community structures

○ churches (CO26, EN35) ○ local business such as barbershop or pubs (CO26)	

Macro-level determinants for self-directed health literacy

The lack of integrated care (EM04, EN24) is the only barrier explicitly mentioned for self-directed education, explicitly appearing in the revision; conversely, education (EN18) and more research on health (CO08) appeared. However, and considering the study results as a whole, facilitators may be hypothesised and further analysed in the section on discussion (e.g., universal access to healthcare and education, integrated care models or policies tackling broader social circumstances, such as deep-routed inequalities, discriminations, or material deprivation).

Collective health literacy: health education programmes

As previously introduced, health literacy can be acquired in a self-directed and individual way and collectively through participation in programmes and health education interventions, or in mutual support groups; most of them are currently following a peer-based structure; and others are led and facilitated by healthcare professionals. When health education programmes and intervention are addressed to hard-to-reach or discriminated populations, challenges may arise during the recruitment and during its conduction and implementation. This section differentiates the micro, meso and macro-level determinants during these two stages.

1.1. Recruitment of persons for health education programmes

This theme explores the barriers and facilitators for recruiting individuals at micro, meso and macro levels; thus, considering their intrapersonal, interpersonal, organisational, cultural and structural settings.

Factors impacting the recruitment at micro-level: intra and inter-personal

The success of the recruitment shown a high dependency on material and economic circumstances of each individual: their ability for paying the programme or for affording the parking fees, public transport costs or tests and procedures needed for preventive actions are essential; also, the time required for reaching the meeting venue, the job and caregiving obligations, and the costs – including the indirect ones (e.g., opportunity costs, or labour hours lost, etc.) – associated with their participation should be carefully considering. Cultural and personality issues should be taken into account: emotional issues, powerlessness, the importance of the

“Wow!” factor when presenting the programme or intervention, and necessities (e.g., safety or confidentiality) and motivations. At the interpersonal level, a major facilitator is the recruiter's trust: community leaders, peers, relatives or persons trusted by the patient or the community, such as highly-committed organisations or community organisations, can foster the recruitment rates.

Table 10 – Recruitment: Facilitators and barriers at micro-level

Facilitators	Barriers
Microlevel – Intrapersonal	

• **Material and economic circumstances**
  • Ability to pay for the programme, if payed (ED7) (EN25)
  • Free car parking (ED4)
  • Public transportation voucher (ED4)
  • Insurance (EN01)
  • Free screening (EN01
  • Internet (EN07)
• **Priorities and individual’s goals**
  • Confidentiality (EN25)
  • Motivate by appealing to a better Quality of life or health outcomes (ED7)
• **Emotional factors and personality**
  • Wow! Factor (ED7)
  • Consider the emotional vulnerability and how it may impact on the reluctance to be recruited (EM15)
	• **Material and economic circumstances**
	  ○ Costs (ED7)(EN07)
	  ○ Travel (ED4)(EN07)
	  ○ Connectivity issues (EN07)
	  ○ Rural (EN07)
	  ○ Travelling times (ED4)(EN07)
	  ○ caring and obligations (ED7) (EN07)
	  ○ Job schedule (EN07)
	• Complex socio-demographic issues related to job and SES (ED7)
	• **Cultural factors**
	  ○ Sensitive issues (e.g., STI) (EN25)
	  ○ Internet and IT-based means are problematic for middle-aged persons, not used to computers and tech (EN07)
	• **Emotional factors and personality**
	  ○ Psycho-emotional problems inhibiting the social relationships (EM15)

Microlevel – Interpersonal	
• Trust in the recruiter (EM15) (EN01) (EN08) (EN09)	

Factors impacting the recruitment at meso-level: organisational and cultural settings

At meso-level, organisational and community factors related to norms and values should be differentiated.

At the organisational level, to offer free or low-cost programmes, considering the socio-economic barriers that may interfere the recruitment or participation in a programme, offering attractive and meaningful interventions, and, also, if possible, offering some type of payments (e.g., transport vouchers) that can diminish the barriers related to costs and travel times discussed at micro-level. The participation of HCPs is also exciting and can act as a facilitator. The needed physical space and the unsupportive organisational managers or colleagues act a significant barrier.

At community level, the role of stigma and the conflict between the programme - or the recruitment means used - with the socio-cultural environment appeared across the studies. As facilitators, it should be highlighted the role of the place, and how to select the appropriate places and actors can drastically increase the success of the process: local health and social work entities, GPs and other HCPs - supposed as trusted recruiters - and opportunistic outreach (e.g., to attend to community events or to promote the programme in critical places for the groups intended to be recruited, such as churches) arose in the studies. Also, the word-of-mouth, determined by the trust in the peer talking about the programme, and the places and type of posters or flyers, as well as the locations in which expose them are present. Lastly, but very important, the intervention should be meaningful for the community in order to ensure that the recruitment is feasible: to work jointly with CSOs, involve families, considering the community leaders and stakeholders, gender-issues and to recruit for interventions able to strengthen community bonds.

Table 9 - Recruitment: Facilitators and barriers at meso-level

Facilitators	Barriers
Organisational	
• Make the programme fun, attractive or an opportunity for socialising (ED7) (EM17) (EN25) • Free or low-cost (ED7) (EN25) • Paid programmes (ED7) (EN25) • Presence by the health service (EM17) (EN08) • Support from the Primary Attention (ED16) • Advertising (EN07) • Translation ,bilingualism (EN34) • For recruiting professionals (e.g., nurses), to approach rural communities (ED12)(EN08)	• Unsupportive managers (ED12) • Have a physical space (ED12) • For recruiting professionals (e.g.,nurses), o large communities (ED12) o urban áreas (ED12) o workload (ED12) o flexibility in the workplace (ED12) • Unsupportive GPs and HCPs in primary attention (ED16)
Community, cultural values and norms	
To recruit in the appropriate place - Local health and social care entities (ED12)) (EN01) (EN08) (EN25) - Local GPs and HCPs in primary attention (ED16) (EN01) (EN08) (EN25) - Incidental encounters in healthcare settings, such as complex and/or chronic care units (EM15) - Informally organised peer support; e.g., two patients going the same day at the same time to chemotherapy (EM15) - opportunistic outreach opportunity (EM17) (EN08) (EN25) o community events (EM17) (EN08) (EN25) o shopping centres (EM17) o mobile services (EM17) o neighbours (EM17) o friends (EM17) - centres of living and social activities (EN01) (EN25) (EN34) o churches (EN01) (EN25) (EN34) o sororities and fraternities; gender-specific health clubs (EN01) (EN25) o barber shops, salons (EN01) (EN25) o Football clubs o Local councils o Colleges and universities (EN25) o Pharmacies (EN25) o Ethnic specific Support grupos (EN25) o workplaces (EN01) - word of mouth (EM17) (EN09)	• Stigma (EN25) • Broader conflict with the socio-cultural environment (EN25)

- transit (billboards, etc) (EN01) - Announcements through the mass media (EN01) (EN25) - referrals (EN09) - community spokesperson (EN01) - community identified centres of influence (clergy, etc) (EN01) - Bulletin boards (EN01) - Easy to read flyers (EN08) - Commercials (EN01) - Online methods (EN25) o Facebook (EN25) o Websites (EN25) o virtual focus groups (EN25) o Google advertising (EN25) - Professional associations (ED12) To give a sense of community; strengthen community bonds (EN25) (EN34) Active support of community stakeholders (EN08)(EN25) Working with CSOs (EN25) Gender issues (ED7)(EM17) • Gender- masculinity: peer-based motivation/competition (ED7) • Gender feminity: verbal (EM17) Facilitator role of nurses as literacy raisers (EM15) Facilitators or trainers from the same community and/or gender (ED7) Involve families (EN34 * Latinos)	

In sum, there are a range of conditions that should be carefully assessed, at meso but also micro levels, during the design and the execution of the health education programme or the launch of a mutual support group; these are summarised in the following barriers and facilitators table:

Table 10 - Key recruitment enhancers and barriers for health interventions, innovations and research projects

Facilitators	Barriers
• **Trust in the recruiter** (EM15) (EN01) (EN08) (EN09) • **Make the programme fun, attractive or an opportunity for socialising** (ED7) (EM17) (EN25) • **Give a sense of community**; strengthen community bonds (EN25) (EN34) • **Free or low-cost** (ED7) (EN25) • **Paid programmes** (ED7) (EN25) • **Presence by the health service** (EM17) (EN08) • **Active support of community stakeholders** (EN08)(EN25) • For recruiting professionals (e.g., nurses), **rural communities** (ED12)(EN08) • **Gender specific** (ED7)(EM17) • Gender- masculinity: peer-based motivation/competitition (ED7) • Gender feminity: verbal (EM17)	• **Costs** (ED7)(EN07) • **Travel** (ED4)(EN07) • **Connectivity issues** (EN07) • **Travelling times** (ED4)(EN07) • **caring and obligations** (ED7) (EN07) • Complex socio-demographic issues related to job and SES (ED7) • Rural (EN07) • Job schedule (EN07) • Unsupportive managers (ED12) • Have a physical space (ED12) • For recruiting professionals (e.g.,nurses), large communities (ED12) • workload (ED12) • flexibility in the workplace (ED12) • Unsupportive GPs and HCPs in primary attention (ED16) • Psycho-emotional problems inhibiting the social relationships (EM15)

• Working with CSOs (EN25) • Support from the Primary Attentin (ED16) • Use public awareness and education campaigns for engaging patients in programmes (EN25) • Free car parking (ED4) • Public transportation voucher (ED4) • Wow! Factor (ED7) • Consider the emotional vulnerability and how it may impact on the reluctance to be recruited (EM15) • Facilitator role of nurses as literacy raisers (EM15) • Insurance (EN01) • Free screening (EN01) • Advertising (EN07) • Facilitators or trainers from the same community and/or gender (ED7) • Internet (EN07) • Confidentiality (EN25) • Translation ,bilinguism (EN34) • Involve families (EN34 * Latinos) • Motivate by appealing to a better Quality of life or health outcomes (ED7)	• Internet and IT-based means are problematic for middle-aged persons, not used to computers and tech (EN07) • Stigma (EN25) • Sensitive issues (e.g., STI) (EN25) • Broader conflict with the socio-cultural environment (EN25)

Factors impacting the recruitment at macro-level: policies and structural conditions

Only the public awareness promoted by governmental administrations and public health entities at the regional and national level appeared as a facilitator; however, considering the factors discussed above, conversely, the establishment of policies aimed at minimising the devastating consequences of social, economic and health inequalities can be critical in order to optimise the participation of most deprived and/or stigmatised communities.

Table 11 - Recruitment: facilitators and barriers at macro-level

Facilitators	Barriers
• Use public awareness and education campaigns for engaging patients in programmes (EN25)	Constructs*: - Policies and resources devoted for tackling and Munising social and economic deprivation and stigma

1.2. Implementation of health promotion and health literacy programmes

Microlevel determinants of the implementation of health literacy programmes

Micro-level determinants are analysed at intra and interpersonal levels. At the intrapersonal level, to see results, having clear expectations about what to expect in the programme are major facilitators: these can foster the participant's sense of agency. Meanwhile, the locus of control is also a facilitator for keep engaged in the intervention. Again, material and economic circumstances pay a major role and individual’s goals and priorities. The social support and the environment, considering each individual's knowledge or previous health literacy, the social and cultural barriers perceived, and the anonymity and privacy arose. Exacerbations and physical health might suppose a barrier for the retainment and personality factors – and how these can determine the motivation and the interaction with the other members of the group - should be taken into account.

At the interpersonal level, to generate safe-spaces, non-judgmental environments, promoting learning and exchanging knowledge and experiences is critical for retaining persons: to share experiences may also confirm the 'normality' of the person as a whole; also, setting goals and implementing changes and challenges together. On the contrary, problems referring to the group dynamic and the interaction between members may arise, and lastly, individuals feeling themselves a 'minority within the group (e.g. younger or elder persons, CALD persons, etc.). Illness-focused groups focused on the problem instead of the solutions and coping aspects, suppose a barrier to continuing the programme. Besides, it may be noticed that power imbalances may appear and that the disclosure of information in groups tends to be less compared to 1:1 counselling. Lastly, leadership issues may appear concerning role, responsibilities, knowledge, previous relationships and conflicts regarding power and professionalism,

Table 12 - Health literacy and health literacy programmes: facilitators and barriers at micro-level

Facilitators	Barriers
Intrapersonal	
- to feel in control; greater sense of agency (ED15, ED7, ED8) - Clear expectations and nature of the programme (ED2) - to see results (ED15) - to involve already (previously) motivated individuals (ED15)	• Material and economic circumstances ○ To live in rural areas without easy access to face-to-face groups (CO33) (EN07) ○ Group schedule (CO08) (EN07) ○ Too far from home (CO08) (EN07) ○ Busyness (CO33) (EM05) ○ Lack of devices (EN01) ○ Vulnerability (ED12) • Priorities and individual's goals ○ Time-consuming (CO33) (EM05) (EN07) ○ To feel that additional support is not needed (ED11) (ED15) ○ To consider that there is not new information (ED15) • Culture and social environment ○ Lack of knowledge (EM11) ○ Social or cultural barriers (EN18) ○ Anonymity and privacy (EN07) • Emotional factors and personality ○ Perfectionism (ED10) which may led to unrealistic expectations (ED10) ○ Only extrinsic motivation (ED15) ○ Unable to maintain the motivation ((ED15) ○ Mood, frame of mind (EM15) • Physical health factors ○ Symptoms or treatment side effects (CO33)
Microlevel – Interpersonal	

- non-judgemental environment; similar backgrounds and experiences (ED11, ED16, ED4, ED5, ED8, EM05, EM12, EM15, EN07, EN19). - Learning from each other (ED12, ED5, ED8, EM05, EM10, EN18) - to set goals and implement changes together (CO35, ED15, ED4, ED5, EM02) - empathy between members (EM09, EM10, EM12) - to share experiences as a confirmation of *normality* (ED8, EM10, EM12) - Information (EM13, EN28) - similar socio-economic backgrounds or circumstances (EM15) - institutional and interpersonal reinforcement and support (CO26)	• **Problems within the group; interaction between members** • **To feel like a minority in the group. Expecting similar participants (EM10) (EM02)(EM09)(CO08)** ○ **Age of participants (CO08); underrepresentation of age (CO08)** ○ CALD ▪ To fail to address ethnic minorities (EM02)(EM09) ▪ Language; No translations available (EM17) (EN18) • **Illness-centric; fewer opportunities and less time available for discussing non-illness related aspects (CO33)(ED8) (EM02)(EN35)** • Groups focused on "negative" problems (ED8) • Less disclosure in groups when compared to 1:1 counselling (EM09) • Power imbalance between participants (EN08) • Online groups: ○ Lack of IT literacy (CO33) ○ Time-consuming (CO33) ○ Reduced intimacy (CO33) ○ Absence of visual cues (CO33) ○ No immediate communication/interaction, diffused focus (CO33) ○ Unanswered questions (CO33 • Leadership issues ○ Peer-leaders do not respond to medical specialised questions (ED5)(EM13) ○ Leaders' role responsibility (EM02) ○ Peer-leaders find challenging to work with previously known peers (ED12) ○ Nurses find challenging to work with patients now acting as facilitors (ED12) ○ Participants are unable to set up and run their own groups after the participation (ED16)

Meso-level determinants of the implementation of health literacy programmes

Meso-level determinants are grouped into organisational and community/cultural factors. To design appropriate and attractive didactic materials at an organisational level, to implement interventions tailored to individuals' needs and provide safe spaces are important facilitators. The costs, affordability, roles, support from healthcare or social care managers of public administration officers, and the organizational culture may be considered potential barriers to conducting successful interventions. These successful interventions are also mediated by the support from HCP, the support and emotional rapport between members in face-to-face groups and the use of online platforms if the flexibility is essential for the target groups or the target group is (relatively) isolated.

Regarding the community level, cultural norms and values, the necessity for power balanced groups may be greater in very discriminated groups; also, the programmes should be gender-tailored, if relevant: gender-tailoring facilitates to take advantage from traditional roles without perpetuating them. Also, if CALD persons are involved, tailored materials and media can be designed and used.

Table 13 - Health literacy and health literacy programmes: facilitators and barriers at meso-level

Facilitators	Barriers
Organisational	
- attractive didactic materials (ED4, CO35) - providing safe spaces (EN19) - Tailor the progress and the scope to individuals' needs (EN02) **Types of groups** HCP role: - Support from HCPs (EN07,EN42) - groups led by HCPs (ED12, ED15, EN39). Face-to-face groups - emotional rapport (CO33, CO35, ED16, ED2, ED4, ED5, ED8, EM08, EM10, EM12, EM13, EM15, EN07) - support (CO33. ED16, ED2, ED4, ED5, ED8, EM02, EM08, EM09 EM10, EN19, EN28) - discussion or information (CO35, ED16, EM10, EM12, EM13, EM15, EN18, EN28) - presence (CO33, ED2, ED4, EN07, EN33) Internet groups - greater flexibility (CO33, EM10, EN04) - rural areas or areas lacking of enough services (CO33, EN04)	• **Limited funding, cost, affordability (EN08)(EN09)(EN18) (EN19)** • Problems in defining the role, lack of definition or clarity (ED12) (EM05) • Lack of support from healthcare and socialcare managing entities EN35 • Telecare support: Difficulties in finding convenient times for calls (ED11) • Lack of follow-up or contact between participants after the end of the programme (ED16) • Organisational pressures (EN10) • The intervention is not made in a timely manner (ED12) •
Community, cultural values and norms	
Balanced power (ED10, ED16, EM10, EM15, EN02, EN08, EN19) gender-tailor the programmes (ED7, ED8, EM02, EM09, EM10): - Masculinity ○ facility obligations (ED7) ○ brotherhood (EM02, EM09, EM10) ○ leadership (EM02) - femininity ○ sisterhood (ED8) ○ sharing of experiences (ED8) Culturally tailored means and materials (CO35, EN19, EN34)	• Stereotyping groups or communities (EM02) • Limited community participation (EN08) • Persons viewed as a number, or as a person at risk (EN19) • Stigma (EN25)[10]

Macrolevel determinants of the implementation of health literacy programmes

As health literacy and education interventions are not implemented at the macro-level, macro-level determinants are not as extensive as observed in other chapters (e.g., in decision-making). However, the patients'/communities' potential for lobbying and advocacy, the cohesion within the communities - in particular, those especially discriminated or counter-hegemonic - and representativeness are macro-

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[10] See also (ED10, EM02, EM15, EM17, EN02)

level facilitators for conducting (at micro and meso levels) health education programmes.

Table 14 - Health literacy and health literacy programmes: facilitators and barriers at macro-level

Facilitators	Barriers
- potential for lobbying and advocacy (EN05, EM05, EN33, EN39) - cohesion (EN05, EN33) - representativeness (EN08, EN28) - committee-based leadership (EM05)	Conversely, - structural and systemic problems for advocacy, social cohesion and establishing social bonds towards lobbysm and activism - lack of CSOs representativeness

Section 3. Adherence, self-management and decision-making

This section analyses the factors involved in the adherence and compliance of patients in healthcare, the self-management of health and, specifically, chronic conditions and the complex processes that decision-making involves; these three themes are divided into facilitators and barriers and, then, subdivided into micro, meso and macro-level factors.

Compliance and adherence

Compliance and adherence define the persons' willingness and skills to follow the treatment instructions and/or the HCPs' guidelines and advice. Both dimensions, further developed in the section on Discussion, are here analysed considering its micro, meso and macro-level determinants

Microlevel – Intra and interpersonal

Motivation, literacy (related to skills and abilities for self-managing and making decisions about one's health), responsibility and commitment are critical facilitators determining the adherence to the treatment. On the contrary, personality barriers and poor health literacy may affect to compliance: personality barriers are mainly related to avoidance, lack of sense of responsibility and disorganized behavior. Other psychological factors are disempowerment and helplessness, to feel the self-management as a burden and distress experienced associated with the diagnosis or the disease. Distress may also be related to socio-economic factors. The lack of health literacy has a vast negative impact due to health misunderstanding, misinformation and misunderstanding.

At the interpersonal level, trust, language and communication skills in the counselling are facilitators promoting adherence, also considering the time devoted to the consultation and the patients' social network (e.g., family support). Fear, mistrust and a perceived lack of privacy act as barriers preventing compliance.

Table 15 - Compliance and adherence: facilitators and barriers at micro-level

Facilitators	Barriers
Intrapersonal	
Motivation • for testing, screening and prevention ○ ability to make more informed medical decisions about risk management (CO06)(CO19) (CO20) ○ Family (CO06) (EM06) ○ helping them more effectively manage their current diagnoses and treatment; enhanced self-management (CO06)	**Individual and personality barriers** (CO10) (CO20) (EM07) (EM08) (EM11) (EM12) (EM16) (EM17) (EN01) (EN05) (EN06) (EN14) (EN17) (EN18) (EN24) (EN38) - Patient disempowerment, helplessness (CO20) (EM17) (EN01) (EN17) (EN38) - Burden of self-management (CO20) (EM07) (EM08) (EN05) - Avoidance (CO20) (EM11) (CO23) (EM17) (EN05)

○ Fearing the consequences (EN34) • for adhering ○ Fear (CO23)(EM06)(EN14)(EN34) ○ Acceptance ▪ acceptance of their long-term condition (ED16) (EN05)(EN29) ▪ Attitude about the seriousness of the disease (CO19) (EN05) ○ Wellbeing ▪ Adherence as needed for preserving life and health (CO09)(EN37) ▪ Previous Sub-optimal health outcomes or results (CO15) (CO19) ○ To enjoy taking the medication (CO09) Individuals' literacy (CO19) (CO20) (EN02) (EN09) (EN15) (EN18) (EN35) (EN45) (EM11) • abilities for self-managing health (CO19) (CO20)(ED9) • Abilities for decision-making (EM11) • Use of data (EN45) Individuals' responsibility: (CO09) (CO15) (EM07) (EN02) (EN05) (EN14) • Accountability for self-caring themselves (CO09) (EN02) (EN14) • taking meds on time (CO09) (EN14) • Personality traits (CO15) (EM07) • High self-efficacy (EM07) • To feel in control (EN05) Commitment to follow-up (CO15) (EN05) (EN09) (EN35) (EN36) • Follow up (CO15) (EN05) (EN36) • Regularity and continuity (EN09)	○ Too afraid to attend the clinic (CO23) ○ Minimisation (CO20) (EM11) (EM17) (EN05) - Disempowerment due to take meds (EM16) (EN05) - Distress associated to the diagnosis or illness (EM12) (EN05) - Distress related to the socio-economic consequences of the disease (EM12) (EM17) - To forget to take the pills (EN05) (EN18) - Sense of responsibility (EN14) - To do not want to take up the HCP's time (CO10) - Insufficiently developed therapeutic relationship (EN05) - To feel good (EM11) - behaviourally disorganized (EN05) - To ignore appointments (EN05) - Lack of motivation (EN05) - Concern about being a burden (EN06) - Mental health issues (EN24) **Insufficient Health literacy** (CO09) (CO23) (CO26) (EM07) (EM08) (EM17) (EN05) (EN18) (EN35) (ED9) - Health misunderstandings and false beliefs: (CO09) (EM08) (EN05) (EN18) - No training received; information demands not met (EM08) (EN18) - Taking days or weekends offs to give the body a break (CO09) - Unattendance to training (EN18) - Do not understand the sense of the recommendations (EN05) - To balance meds without medical supervision (EN05) - Lack of biomedical knowledge (CO23) (EM08) (EM17) (EN05) (EN18) (EN35)
Interpersonal	
• Trust - in the HCP: (CO19) (CO20) (EM07) (EM08)(EM12) (EN05) (EN14) • Appropriateness of terms and language used in the counselling (CO22) (EM07)(EM12) (EN05) (EN09) (EN40) ○ specific recipes and examples (EN05) ○ open two-way communication (EN05) (EN09) • Enough time for counselling (EM12) (EN05) (EN14) (EN40) • Trust (in the patient) (CO19) (EN05) (EN09) • Family and loved ones' support (CO06) (EM06) (EM08) • To feel cared (EN05) (EN09) (EN18) • Face-to-face outreach (EM17) (EN05)	**Fear and mistrust** (CO06) (CO23) (ED9) (EM04) (EM07) (EM08) (EM16) (EM17) (EN01) (EN02) (EN09) (EN36) (EN42) - Medical mistrust (CO06) (EM04) (EM07) (EM08) (EM17) (EN01) (EN09) (EN36)(EN42) - Stigma and sense of stigma (CO23) (ED9) (EM04) (EM16) (EM17) (EN01) (EN02) (EN36) - Disclose to social environment, networks, friends, etc. (EM04) (EM16) Lack of privacy (CO06) (EM04) (EM07) (EM16) Insensitive behaviour in HCPs (EM08) (EN01) (EN09)

Meso-level – Settings

Facilitators and barriers of adherence at the meso-level are analysed at the organisational and community levels (norms, culture, and values).

Firstly, the availability of additional health literacy resources plays a major role in fostering adherence (e.g., health education programmes or peer-supported groups). Likewise, the time waiting for an appointment, the goal-setting abilities of the patient and how the care team can help the patient to establish objectives, the sense of ownership and responsibility concerning their centre of reference and the costs, location and access of care centre are important facilitators at the organizational level.

At the community level, no facilitators have been directly found; in regards barriers, it must be emphasized the inadequacy between the medical culture and the community culture: it might be a barrier in terms of expectation management, may generate the distrust of the community (that is usually founded on past historical experiences and cultural values), or the patients might perceive a lack of compatibility between medical guidelines and their own lifestyles, especially if these lifestyles are strongly cultural mediated and deep-routed in their values. The emphasis on medications and illness instead of health and prevention and the lack of attention that chronic patients (in contrast to acute patients) may perceive by the healthcare institutions are also barriers to adherence. Social and individual customs, as previously mentioned, culturally mediated, in regards the diet, alcohol and other substances ab/use, taboo topics, or parental surveillance in youngsters might interfere with the patient adherence to treatment and the establishment of a therapeutic relationship with providers.

Table 16 Compliance and adherence: facilitators and barriers at meso level

Facilitators	Barriers
Organisational	
• Additional health literacy facilitated, such as peer-support activities, health education programmes, or MSG (EN02) (EN09)(EN15)(EN18) (EN35) ○ HCPs participating in peer-supported groups (EN35) • Short wait for appointments; patient-initiated appointments scheduled on a drop-in or pre-booked basis(EN02) (EN09) • sense of ownership and responsibility of patients in respect of their centre of reference (EN02) • motivating care team; goal-setting (EN05) (EN15) • Mobile unit (EN09) • Easy access (EN09) • No cost for care (EN09) • Respect/care for patients (EN09) • Friendly and efficient staff (EN09) • Work environment (EN14)	Constructs(*conversely): - No sources of additional health literacy available - Long wait for appointments - Lack of engagement and lack of sense of ownership of patients in respect to their centre of reference - Costs, mobility issues, transportations and material circumstances
Communities, norms and values	
Constructs(*conversely): - Adequacy between medical culture and community culture, as	**Inadequacy between medical culture-community culture** (CO20) (EM07) (EM17) (EN05) (EN18) (EN25) (EN38) - HCP's expectations cannot be met or are too difficult to follow (CO20) (EM07) (EN05) - Cultural factors, social distrust (CO06) (EN36) (EN42) - Chasm between the guidelines and the practical reality of their lifestyles in their community (EM07) (EN05) (EN18)

well as individuals' customs and behaviours - Preventive care in place	- The more chronic the illness, the less attention they receive (EM17) (EN25) - Assumptions that medication is the be-all and end-all (EN38) **Social and individual customs** (CO09) (CO20) (CO26) (EM07) (EN24) (EN35) - Diet (CO09) (EM07) (EN35) o Socialisation implying to share food (EM07)(EN35) - Holidays (CO09) - Alcohol consumption (CO09) - Substance abuse issues (EN24) - Relatives and, specifically, parental surveillance (CO20) - Taboo subjects (CO26) Lack of preventive care (CO26) (EM07) (EM08) (EM17) (ED9) o Gender-based: masculinity (CO26) (EM08); feminity (EM07) (EM17) o Ethically based: African-American (CO26) o Sexuality-based: WSW (ED9)

Macrolevel – Policies

At macro-level, studies highlighted the importance of the socio-economic and socio-cultural factors in chronic care and patients' compliance; financial burdens, lack of social support and network, socially determined sedentarism, or problems in accessing healthcare are barriers to adherence that individuals may experience but to overcome those challenges is highly dependent on policies and governmental organization. Integrated care and care and the awareness of social determinants of health would reduce the impact that these circumstances have on persons' and communities' adherence and compliance to medical treatments.

Table 17 - Compliance and adherence: facilitators and barriers at macro-level

Facilitators	Barriers
• Awareness of social inequalities on health, illness and healthcare (EN02) (EN24) o Trauma and cultural awareness (EN02) o addressing people's social needs (EN02) o housing (EN02) (EN24) o food (EN02) (EN24) o financial issues (EN24) • better integrated care (EN05)	**Socio-economic and socio-cultural issues** (EM04) (EM06) (EM07) (EM08) (EM12)(EM17) (EM08) (EN01) (EN09) (EN29)(EN30) (EN35) (EN36) (EN42) - Financial burdens (EM06) (EM12) (EM17) (EN01) (EN09)(EN29)(EN30)(EN36) - Lack of social network: families and friends living too far, limited contact, etc. (EM08) (EN01) - Socially determined sedentarism or low physical activity (e.g., caring obligations, no facilities available even for walking) (EM07) - Overscheduled clinicians (EN09) (EN42) o Frequent rescheduling, cancel appointments (EN09) (EN42) o Inoperable equipment (EN09) - Rural areas (EN35) - Lack of sustainability/funding issues in the services provided (EN09) - Language barriers, necessity to use interpreters (EM04)

Self-management

Self-management of health for the chronic patient is a complex term that involves voluntary adherence to the treatment and a proactive approach of self-care, requiring an increased health literacy (and so, literacy in general), sense of agency and abilities for making informed decisions.

Microlevel: Inter and interpersonal determinants of self-management

At the intrapersonal level, the most important facilitators of self-management are the education, the integration of knowledge acquired in the patient's everyday life, the patients' motivation and goal-focused mindset, ability to self-reflection, the proactive acceptance of the disease, the risk awareness and their ability for self-organizing and schedule pleasurable but still valuable and healthy activities contributing to the reinforcement of healthy habits (diet, exercise, emotional health, etc.). However, barriers to a proactive self-care may arise if the patients experience difficulties in understanding or managing the new living conditions (e.g., lack of HCPs support, changing living arrangements, comorbidity and health 'obligations' perceived as unfeasible). Patients might feel their support needs unmet, or feel overwhelmed by a vast amount of information, medical records, medications and self-care habits to acquire. Also, some patients might consider that, due to their schedule, self-management of health is not possible. Also, financial hardship is a very important barrier to self-management, jointly with low self-efficacy.

At the interpersonal level, primary facilitators are the family support - particularly for some minorities such as Latino and African-American communities - and the job, specifically, the patient's alliances in the workplace and the meaningfulness perceived in his/her job. Barriers to self-management are family problems, loneliness, and the potential negative impacts of the illness on loved ones, and the communication challenges experience in the interaction with HCPs (lack of time and dismissal)

Table 18 – Self-management: facilitators and barriers at micro-level

Facilitators	Barriers
Intrapersonal	
- Education ○ Knowing or learning self-management needs (CO31)(ED2) (ED5) (ED6) (ED8) (EM09) (EM12) (EM13)(EN01) (EN29) (EN34) (EN45) ○ Understanding challenges (CO15)(CO27) (CO31) (ED2) (EN29) (EN45) ○ Previous education (CO13)(CO19) (EM16) ○ Constellation of symptoms (CO31) (EN29) - Practical knowledge able to be integrated in patients' life (CO15)(CO27) (ED15) (ED2) (ED5)) (EN05) (EN29) - Motivation; Goal-focused (ED15) (EM12) (EM16) (EN01) (EN02)) (EN05) (EN14) (EN40)	**Difficulties in managing the new living conditions (CO04)** (CO08) **(CO15) (CO31) (CO36) (EN01) (EN14) (EN37) (ED10) (EM04) (EM07) (EM08) (EM12)** (EM13) **(EM16) (EM17)** (EN05) **(EN23) (EN24) (EN34) (EN35)** - Lack of HCP's support for implementing self-management strategies (CO15) (CO36) (ED10) (EM07) (EM08) (EM17) (EN24) (EN35) - Changing living arrangements (CO04) (CO15) (CO31) (CO36) (EN01) (EN14) (EN37) - Comorbidity, multiple health issues (CO04) (CO31) (EM13) (EM17) - unfeasible health-obligations such as self-care, exercise or diet (EM07) (EM12) (EM13) (EM16) (EM17) (EN35) (EN05) (EN24) ○ emotional stressors (EM12) (EM13) (EM16) (EN24) ○ nutrition unaddressed (EM12) (EN05) (EN35)

- Self-reflection (CO15) (CO26) (CO36) (ED11) (ED16) (EM08) (EM09) (EM12) (EM16) (EN02)) (EN05) (EN40) - Acceptance (CO36) (ED11) (ED16) (EM16) - The ability for scheduling pleasurable and useful activities (CO15) (ED15) (ED2) (EN05) - Risks awareness (EN01) (EN02) (EN14) - (Transversal) Healthier habits o Diet (CO15) (CO35) (ED11) (ED15) (ED5) (EM04) (EM08) (EM16) ▪ Traditional diets (EM04) (EM08) o Exercise (CO15) (ED11) (ED15) (ED5) (EM04) (EM16) o Emotions, mental health (CO32) (EM16) (EN02) (EN05) o Prevention; general (EN01) (EN02) o Daily routine (EN02) (EN14) o Body satisfaction (ED15) o Sleep (CO15)	o Caregiving (EM17) o physical needs conflicting with the self-management (EM12) - support needs unmet (CO04) (CO31) (EM04) (EM07) (EM08) (EM12) (EM16) (EN24) - to manage medical demands (CO04) (CO31) (EM07) (EN24) - to manage a vast amount of information and medical records (CO31) (EM07) (EN23) - unfeasible schedules (CO08) (EN24) (EN34) - HCPs assuming a previous health literacy higher than the actual one (EM17) **Costs; financial hardship (CO19) (EM03)(EM04) (EM13) (EM16) (EM17) (EN01) (EN09) (EN18) (EN24) (EN30) (EN34) (EN35) (EN36)** **Low self-efficacy (CO36) (CO37) (EM04) (EM07) (EM17) (EM16) (EN02) (EN19) (EN24) (EN25) (EN32) (EN36)** - Avoidance (CO36) (EM04) (EM17) (EN32) (EN36) o to seek care too late (EM04) (EN23)(EN36) o unacceptance (EM06) o Faith, religion (EM07) - Trauma (EN02) (EN19) (EN24) - Lack of flexibility (CO37) - Fear of failure (EM07) (EM17) - Self-stigma (EM16) (EN25) - lack of health education (CO36) (EM07) (EN01) (EN23) - misinformation (ED10) (EM07) (EN01) **Low self-care involvement (CO06)(EN01)** - less involved (previously) in his/her own health (CO06)(EN01) - poor self-care; don't' know how to prevent (EN01) **Domestic and gender-based violence (EM13) (EM17)** **Low literacy (CO23) (EN23)** **Mental health problems (EN24)** **Substance abuse (EN24)** Previous bad experiences (EM16)
Interpersonal	
- Family support (CO06)(CO08) (CO37)(ED14) (EM04) (EM08) (EM10) o acknowledgement of family role in African-American community (CO06) o migrants, interpreters (CO37) (EM17) o Responsibilities and obligations (ED14) (EM08) (EN14) o Married or committed/stable couple; wife/husband (CO13) (EM08) (EM10) - Work; Alliances in the workplace; work as meaning (EM08) (EM16) (EN01) (EN14) (EN29)	**Family matters and problems (CO04) (CO06) (EM04)(EM04) (EM07) (EM08) (EM12) (EM13)(EM15) (EM16) (EM17) (EN19) (EN25)** - potential negative impacts in the family (CO06) (EM04) (EM07) (EM12)(EM15)(EM16) (EN19) - loneliness (EM13)(EM16) (EN19) - caregiving as isolation (EM17) - uprooting (EN19) (EN25) **Communication challenges with the HCP (CO05) (CO10) (CO36) (ED10)** - lack of time for communicating well in the medical consultation (CO10) - Dismissal (EN02)

Meso-level: settings, organizational and cultural determinants of self-management

The meso-level comprises all factors at organisational and community levels. On the one hand, at the organisational level, the most important facilitators for fostering the patients' self-management are the record and follow-up of treatment and progress, the alliances established by the healthcare facility with the community-based organisations, their efforts in targeting the individuals' behaviours, the availability of screenings and other preventive measures, logistics-related factors and the participation of minority clinicians (if it is relevant for the area). Waiting lists, rushed clinicians and, depending on the target, mixed groups might be barriers for self-management.

On the other hand, at the community level, social ties and support, *familism*, the establishment of culturally rooted informal alliances (sisterhood and brotherhood) and religion or spirituality can act as crucial facilitators and nudges for fostering the individuals' self-management. The lack of culturally sensitive communication and tailored care may result in a barrier, fostering distrust and reluctance in communities; also, the deprivation, previous low levels of health services utilization, stigma and the existence of effective treatments and, so, the increased life-expectancy for severe diseases may be detrimental when tackling self-management of chronic health.

Table 19– Self-management: facilitators and barriers at meso-level

Facilitators	Barriers
Organisational	
- Record and follow the treatment plan and track progress (CO19)(ED13) (ED6) (ED8) (EM08) (EM12) (EN29) (EN45) - Alliances: clinical/research facilities with community-based organisations (CO26) (EM08) (EN01) (EN19) (EN24) - Efforts for targeting individuals' behaviours (CO26) (EM12) (EM13) (EN01) - Minority clinicians (CO26) (EM17) (EN01) - Logistics ○ Location (CO29) (EM17) (EN09) ○ Parking (CO29) ○ Results on time, timely manner (CO29) ○ Face to face (EM17) ○ Mobily units (EN09) ○ Ambulance services (EN14) - Screening (CO26) (CO29) (EN01) - Testing positive in genetic tests (CO06)	**To wait too long for an appointment (CO10) (EN24) (EN34) (EN36) (EN39)** ○ some of them, will use the Emergency Department (EN24) (EN39) **HCPs rushed (CO10) (CO31) (EM17)** ○ poor communication between HCPs in charge; lack of integration (CO31)(EM17) Mixed groups; eg., women and men (CO23)
Communities, values and norms	
- Social ties and social support (CO08) (CO35)(ED13) (ED14) (ED6) (ED8) (EM08) (EM09) (EM10) (EM13) (EM16) (EN14) - Familism; family support (CO06)(CO08) (CO37)(ED14) (EM04) (EM08) (EM10)	- **Communication challenges at community level; no culturally sensitive/tailored communication; inappropriate messages (CO06) (CO12)**

- Sisterhood (CO06) - Brotherhood (EM09) (EM15) (EN40) - Stay connected with the support system (CO08) (CO35) (EM08) (EM16) - Faith, religion (EM04) (EM08) (EM13) (EM16) (EN01)	**(CO23) (CO37) (EM04) (EM07) (EM17) (EN18)** o problematic translations (CO23) (CO37) (EM04) (EM17) o distrust in the translation systems (EM04) (EM07) o culturally-challenging explanation of diseases (CO23) (CO37) (EM17) (EN18) o no shared understanding patient/s (minorities)-HCPs (CO23) (CO37) (EM07) (EN18) - **Communities or groups with low levels of resource utilisation (EN01)(EN02) (EN19)** - **Distrust, reluctance to the authority, including the medical system (EM07) (EN02) (EN19)** - Stigma (EM16) (EN02) (EN19) (EN25) - **Existence of effective treatments (EN34)** - **(Normalisation) Increased life-expectancy of persons with severe diseases such as VIH (EN34)** - Racilisation (EN01*) - Assumption of the destination culture as a whole, and abandonment of traditional diets, exercise, etc. (EN18)

Macrolevel: policies, systemic and structural determinants of self-management

At the macro-level, policies addressing material resources and living conditions, outreaching minorities and fostering the social awareness and knowledge about the disease contribute to self-management of chronic conditions; on the contrary, the lack of social policies for meeting necessities, such as housing, access to care, groceries and safety, undermine the abilities and possibilities of individuals for implementing efficient self-management strategies and behaviours.

Table 20– Self-management: facilitators and barriers at macro-level

Facilitators	Barriers
• Material resources, life conditions (CO32) (ED14) (EN01) (EN02) (EN19) (EN24) • Engagement of the hard-to-reach; Increase the outreach of minorities (CO26)(CO32) (EM08) (EN01) (EN19) (EN24) • Social awareness about the disease (CO26) (EM08) (EM15) (EM16) (EN01)	**Lack of social policies for meeting basic needs; basic needs unmet (EM04)(EM13) (EN02) (EN17) (EN24) (EN34)** - housing situation (EN02) (EN17) (EN24) (EN34) - Problematic access to care due to logistical reasons (EM17) (EN23) (EN24) o Rural (EN23) (EN35) o Remote areas (EN39) o No car available (EM17) (EN23) o No transportation (EN24) (EN34) - No groceries (EN17) (EN35) - No parks and trails (EN17)(EN35) - Poor infrastructures (EN17) - Unsafe and deprived neighbourhoods (EN17) - No screenings (EN01) - Technology barriers (EN01)

	- Potential negative consequences or risks of testing (EM03) - Fear of authorities (EM03) (EM13) (EN19) - Deportation (EM13) **Poorly tailored services considered deprived groups and persons (EN30) (EN34)**

Decision-making

Decision-making is the process of considering the self-management of care, treatment, options, and patients' choices; decision-making is analysed through its micro, meso and macro-level factors and determinants, enlightening which barriers and facilitators may impact this process.

Microlevel – Intra and interpersonal determinants of decision-making

Intrapersonal level facilitators to active decision-making are mediated by the perception of the knowledge as a source of control by patients, their resources (information, education, health literacy and abilities for conducting informal education, socio-economic resources or self-management abilities) and psychological factors (self-efficacy, proactiveness, preferences, or sense of agency). On the contrary, barriers are related to psychological factors (patients deferring responsibility for their care, lack of desire for information, self-dismissal, powerlessness or avoidance) and the potential lack of resources (lower education, and familiar influence, financial hardship, lower use of IT tools), including health education factors (lower literacy, sceptical patients or patients with limited self-management possibilities).

On the one hand, **interpersonal facilitators** are mainly founded on joint decision-making about treatments, collaborating, supporting the creation of action plans and goal-setting through a power-sharing and shared responsibility and understandings perspective from both the provider and the patient. Confrontation is also a facilitator: some patients may even, prepare in advance for a consultation or ask more questions, raising discussion. Providing detailed and accurate information, focused on processes, explicit recommendations, and offering diverse options is a facilitator for decision-making proactively. On the other hand, **barriers** to provider-patient interaction are to de-emphasise the patients' role, minimise autonomy, dismiss the experiential knowledge, or even exhibit a harsh confrontation style. Also, the inappropriateness of the information provided (vague, brief, simplistic or excessive) or the lack of time devoted to the consultation are barriers. Some patients might also be labelled as *difficult* patients. Other barriers are related to the patients' environment and, specifically, the relatives and their role: relatives might dismiss the patient, devaluing or invalidating his/her experiences or abilities for making informed decisions; even some times goals are family-centred instead of person-centred.

Table 21 – Decision-making: facilitators and barriers at micro-level

Facilitators	Barriers
Intrapersonal	
The patient can perceive the knowledge as a source of control (CO01) (CO08) (CO13) (CO14) (CO22) (CO27) (ED14) (EM08)(EM12)(EN01) (EN03) (EN09) (EN39) Patients' resources: o The patient's informational needs are being met (CO13) (CO22) (CO27) (ED14) (EM08)(EM12)(EN01)(EN03) (EN09) (EN23) (EN39) o Broader education (CO01) (CO08)(CO20) (CO27) (EN23) o Self-directed health literacy ▪ Internet (CO08) (CO27)(EM12) ▪ Books (CO08) ▪ Their own research (CO08) (CO27) o Higher SES (CO11) - Self-management abilities (CO19)(CO20) (CO31) - Patients' abilities and treatments goals aligned (CO19)(CO37) (ED15) (ED16) (EN39) Psychological aspects - **Self-efficacy (ED16)(EM11) (EM12))(EM15) (EN06) (EN14) (EN15) (EN16) (EN38) (EN39) (EN40)** - **Proactiveness (CO27) (ED16) (EM11)(EM12))(EM15) (EN06) (EN14) (EN16) (EN38) (EN39) (EN40)** - Patients' preference in decision-making (CO07) (CO08) (EM11)(EM12)(EM15) (EN02)((EN39) - (CO19)(CO37) (ED15) (ED16) (EN39) - Urgency perceived impacts on the rapid decision-making (CO06) (CO07) (ED16) - Need for psycho-emotional work (CO20) (EM12) - Peer pression (EM09)(EN01) - Positive thinking (ED16) - Sense of agency o Set priorities (CO02)(CO20)(CO37)((ED15) (ED16)(EM12) (EN14) (EN15) (EN39) o Responsibility for their own care (CO01) (CO02) (CO08) (CO11) (CO27))(CO29) (EN15) (EN38)(EM11) ▪ Sense of accountability (CO02) (CO08)	Psychological factors - Patient **deferred responsibility** for the medical management (CO01)(CO11)(CO14) (CO20)) CO22) (CO32)(CO37)(ED14)(ED6)(EM11) (EN06) (EN23) - Lack of desire for information (CO06)(CO08) (CO14) (CO20)(CO22)(CO32)(CO38) (ED6) (ED16) (EM04)(EM07) (EM11)(EN01) (EN05) (EN06) (EN23)(EN32) o Don't want to know (CO06)(CO08) (CO32) (ED6) (EM11)(EN01) (EN05) (EN06) (EN23) o Lacking motivation (CO14)(CO32) (ED16) (EM04)(EN32) o Less involvement in self healthcare (CO06) (CO38) (EM07) (EM11) (EN01) (EN05) o No interest (CO08) (CO20) (CO22) (CO32) (EN01) (EN23) - Self-dismissal (CO10) (CO11) (CO14) (ED6) (EM11) (EN01) (EN11) (EN23) (EN28) (EN35) (EN36) o I don't know (CO11) (CO14) (ED6) (EM11) (EN01) (EN11) (EN23) (EN28) (EN35) o Don't seem themselves important enough (CO10) (EN36) o Lack assertiveness (EM11) (EN21) - Powerlessness (CO08)(CO11)(CO14) (ED14) (ED15)(EM07) (EM11) (EN01) (EN02) (EN35) - Avoidance (CO20) (CO35) (CO36) (EM11) (EN05)) (EN11) (EN15)) (EN19) (EN21) (EN28) (EM08) (EM11) o Patients holding information (EM11) o Fear (CO35) (EM08) (EM17) (EN19) (EN24) o HCPs don't want to hear us (CO19) o Ignoring appointments (EN05) o Lack of confidence; Too shy (EN11)(EN21) (EN28) - Trust (CO11)(CO14) (ED14)(EM11) - Feeling devalued (ED16) (EN01) (EN11) - Fear and uncertainty (CO06) (CO11) (CO14)(CO20) (ED14) (EN01) (EM04) o Shocked or at risk (CO11) (ED14) o Scared, fear (CO14)(CO20) - Stress (EM04) - Fear of being a burden (EN06) (EN36) (EN42) - **Disenchantment** (CO27) (EN01) (EN36) - **fear of being labelled (**CO06) (EM16) (EM17) - it's in God's hands (CO06)(EM07) - **Loneliness** and isolation (EM04) o Patients' resorces - **Lower education** (CO07)(CO09) (CO11)(CO38) (EN23)(EN28) o Quantitative information without hedging associated with lower education (CO07) o Better acceptance of HCPs' confrontational and directive styles in lower ed groups (CO09)(CO11)

(CO11) (EN15) (EN38) ▪ Making sure that what they are giving you is the best thing (CO01) (CO08) (CO11) (CO27) ▪ making sure that it is suitable for you (CO01) (CO08) (CO11) (CO27)(CO29)(EM11) o Looking for a second opinion (CO01) (CO08) (CO11) (CO13) (CO27) (ED16) o Networking with other people with the same disease/survivors (CO08) (CO27)(EM10)(EM12))(EM15) (EN10) o To choose a physician they trust (CO11) (EN23) (EN38) o Negotiation (CO20) (EM15) (EN39) o To postpone treatment (CO08) (CO14)	o Lower ed patients unquestioning the medical advice (CO11) o HCPs assumed not everyone would be capable of taking responsibility of his/her own self-management (CO38) (EN23) - Familiar influence (CO06) (CO17) (ED16) - Afraid to be **ill-perceived** (EN36) - HCPs' personal tone and increased details increased adherence (CO13) - Informed decision-making for screening were not adhered (CO26) - Problems conceptualising the involvement in the decision-making itself (EM11) - Material and socio-economic factors o Costs and financial burden (EM06)(EN01)(EN32) o Low use or access to IT (CO06) - Concerned about privacy (CO06) - Low risk situation (CO11) Health education factors - Lower health literacy (CO14) (CO19) (CO22)(EM08) (EM11) o Lower education (CO07) (CO22) (EN23) o More satisfied if lower education (ED14) - Suspicious skeptical (CO14) (ED16) (EM07) (EM09) (EM11) (EM16) (EN01) (EN18) o Disbelief of science and medical knowledge's limitations (CO14)(EM11) o Doubts about the aggressiveness of a disease, such as cancer (CO14) - Insufficient self-management possibilities or skills (CO19) (CO31)(EM11)(EM12) o Fear of engaging in peer-support because of the HCPs may think that they don't have the skills for self-manage their own health (EM12) - Independent research for information (EM08)
Interpersonal	
- To jointly decide about treatments (CO01) (CO02)(CO13) (CO14)(CO29) o Collaboration (CO08) (CO11) (CO27)(CO29)(CO37) (CO38) (ED14)) (EM11))(EM15) (EN02) (EN06) (EN09) (EN32) (EN36) (EN40) ▪ Collaborative action plan (CO01) (CO02) (CO07) (CO08) (CO27) (CO29) (CO37) (CO38) (ED14)((ED15)) (EN09) (EN15) (EN32) • Nurses supporting the goal setting (CO02) (EN15) • GPs supporting goal	HCPs – Patients interactions: - Deemphasising the patients' role, minimises autonomy (CO07) (CO09) (CO13) (CO23)(EM06)(EM12)(EN06)(EN10)(EN15) (EN23)(EN33) (EN39) (EN40) o Experiential knowledge of patients being disregarded (EN10)(EN15) (EN23) o Dominant HCPs (EN10) (EN33) (EN40) o Patient deferred responsibility for the medical management (EN06)(EN42) o Clinicians' reactions to disclosure (CO15) (CO20) (EM11) (EM17) (EN14) ▪ HCPs dismissal of patients (CO20) (EN01) ▪ Discouraging and accusing (EN14) (EN24) ▪ Intimidation (EN24) - Inappropriateness of the information provision o Brief and vague information (CO07)(CO08) (CO09) (CO23) (CO26) (EM08) (EM11) (EN39) (EN40)

setting (CO38) (EN15) (EN23) • Counsellors (ED15)(EN05) ▪ Sharing of power ((CO27)(CO29)(EM11)(EN02) ▪ Shared responsibility (EN06) (EN36) (EN38) (EN40) ▪ Shared understandings (EN10) (EN36) (EN40) o Confrontation (CO08) (CO27) (EN02) (EN40) ▪ Prepare for the medical consultation in advance “arm with some information to go to your doctor” (CO08) (CO22) (CO27) ▪ Questioning: (CO11) (CO13) (CO14) (CO20) (ED16) • Patients asking questions affecting negatively the adherence (CO13) (CO14) • Discussion about alternative medicine (CO07)(EM08) - To inform and/or convince the patient for following a treatment (CO13) (CO07) (CO29) (CO38) (EM11) (EN23) o Providing impersonal information to the patient (CO07) (CO13) (CO22) (CO29)(EM11) (EN09) ▪ Impersonal tone+increased details=higher anxious preoccupation, intention to adhere, and satisfaction (CO13) o Focused on processes (CO02) (CO07) (CO13)(CO14) (CO29) (EN32) (EN36)	o Simplistic messages; over-simplification (CO26) (EM06)(EM08) (EM11) o Overwhelmed, excessive information (CO31)(ED16)(EM11) (EM12) o Providing information without hedging (CO07)(EN33)(EN40) o Condescending doctors (EN02) (EN23) - Time devoted to the consultation o No time (EM04)(EM11) (EM12)(EN15)(EN23)(EN32) o Concerned about the HCPs’ time (CO10) (EN06) (EN36) (EN42) - Lack of trust o Labelled as difficult patient (CO01)(EN23) (EM17) ▪ Questioning (CO01) ▪ “Good patients” (EN23) ▪ Psiquiatrisation/patologisation of patients (EM17) • Women, “hypochondriac” (EM17) o Lack of confidence in the family physician (CO19) (CO35) (EM08) (EM17) o Trust (CO11) (EM17) - Confronting (CO01)(EM11)(EN10) - Culture (CO15) (EM04) - HCPs’ expectations are not met (CO19) Patients, relatives and HCPs - Relatives dismissing the patient making more difficult the decision-making (EM06) (EN32) (ED16) o Devaluing and invalidating the patient (ED16) - Goals are family-centred instead of person-centred (CO37) (EN32) - Gate-keeping carers (EN32) - Carer and patient cannot reach an agreement (EN32) - For not knowing (CO06) - Culture (for not raising the voice) (CO17) - Caregivers don’t ask questions (CO10) - Caregivers don’t engage in healthcare (CO10)

○ Explicit recommendations (CO07) (CO29) (CO38) (EM11) (EN06)(EN32) ▪ As early as possible; timely (EN32) ▪ Posponed once the patient reached certain level of acceptance (EN32) ○ Causative statements (CO13)(EM11) - To decide between two/more different treatments (CO13) (CO27) (CO31) (CO38) (ED16) (EN09) ○ Diverse options (CO31) (EN09)	

Meso-level – Settings

At the meso-level, organisational and community factors should be analysed. At the **organizational level,** humane care seems to be a major facilitator (probably related to the interpersonal facilitators discussed above); on the contrary, problems in translating, financial resources, low IT infrastructures, and the healthcare facility's location are barriers. At the **community level**, culture might act as a barrier but also as a facilitator: as a barrier, the profound distrust in healthcare professionals and, in general, in authorities may undermine the decision-making process; the power imbalance between patients and providers, mainly if patients come from historically discriminated communities, is also a challenge in decision making. However, culture can be a facilitator: depending on the value attributed to the assertiveness and proactiveness, and the family structures, as well as the social bonds between the communities, it can have a positive impact on decision-making.

Table 22 – Decision-making: facilitators and barriers at meso-level

Facilitators	Barriers
Organisational	
Humane care, good treat (ED14) (EN06)	- Problems in translating (language) information during the consultations/counselling (CO37)(EM04) - Financial and material resources ○ Low funding and limited resources in clinics (EN32)(EN34) ○ Waiting lists (EN34) - Low access or adherence to IT tools (CO32) - Location of the hospital or clinic (EN32) (EN06)
Community, cultural values and norms	
- Culture (CO15)(EM11)(EN01)(EN02)	- **medical mistrust;** Profound distrust in health professionals and authorities **(**CO06) (CO11) (CO19) (CO20) (CO27) (CO35) (ED16) (EM07) (EM08) (EM09) (EM11) (EM16) (EM17) (EN01)) EN18) (EN19) (EN24) (EN36) - governmental mistrust (CO14) (EM09) **(**CO06) (CO35)

	○ Negative experiences with law and authorities (EM09) (EM16) (EN01) (EN19) - **culture (**CO06) (CO35) (EN19) (CO11) (ED9) (EM17) ○ Historical atrocities (CO06) (EN19) ○ (Excessively) respectful attitude; deferential (CO11) (EM17) (EN06) ○ *It is our generation* – older persons (CO11) (EM17) - Power imbalance (EN11) (EN28)

Macrolevel – Policies

Again, at macro-level, factors related to policies are determinant. Policies contemplating the social determinants of health, a critical analysis of societal power differentials, and promoting the staff's multidisciplinarity will positively impact decision-making. Stigma, lack of culturally-tailored care, discrimination in access to insurance and healthcare, and men's dominance might negatively impact and can be considered a barrier.

Table 23– Decision-making: facilitators and barriers at macro-level

Facilitators	Barriers
- Social determinants of health (EN01)(EN02) - Critical analysis of power differentials (EN02) - Multidisciplinary (EN32)	- Stigma (EM16) (EM17) (EN09) - Lack of culturally-tailored care (EM04) - Insurance discrimination (CO06) - Dominance of men in healthcare (EM17)

Section 4. Empowered individuals, empowered communities

This section is subdivided into two subsections: the first one concerns communities and their empowerment within a broader social framework, and the second one responds to the individuals as patients and the patients' autonomy and related psycho-emotional, social and cultural factors, including the living experience of the disease and its relationship with the previous chapters.

The rationale behind talking about empowerment only when referring to communities – except for citations and paraphrases - is that *empowerment* is founded on the change of structural conditions. Thus, it is impossible at the individual level: sole individuals cannot be empowered by themselves if the structural and systemic conditions remain the same. Individuals, however, can foster their autonomy: the consideration of individuals as social, cultural, economic, and moral agents have a direct and very relevant impact on the empowerment of communities, in particular the most socially excluded and/or discriminated ones. At the same time, the empowerment at the community level can raise the sense of autonomy, control and the material, psychological, social and cultural conditions of its members.

1.2. Collective empowerment: empowered communities and societal change

Meso-level determinants: culture, values, norms and organisations.

Facilitators are all referred to meso-level settings; how these conditions concerning groups and cultural settings impacts on macro-level are well-reflected on the literature (Dahlgren and Whitehead 2007; Whitehead 2007) further explained in the section on the discussion. Community empowerment is locally based, founded on partnership and requires a multistakeholder approach: HCPs aware of social and environmental determinants of health, community participation through activism, advocacy, information sharing and cultural pride are critical for empowering stigmatised, discriminated and/or socially marginalised communities.

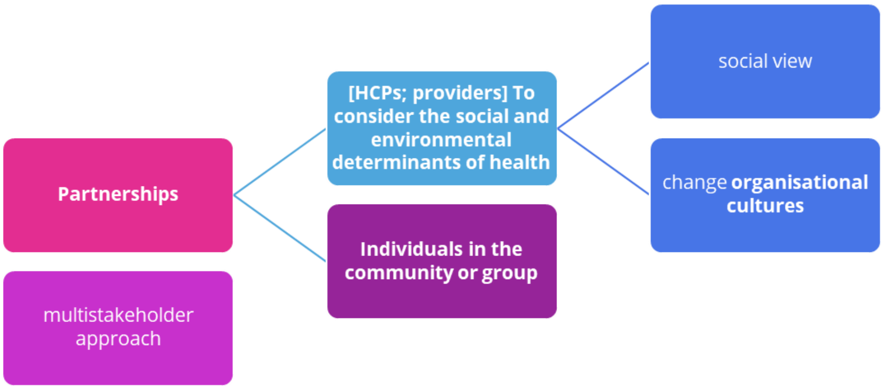

Figure 12 - Community empowerment and partnerships

Main barriers, **also at meso-level**, for reaching the community empowerment are the stigma and, then, the stereotypes founding these pre-assumptions; material, social and financial circumstances play a major role in the disempowerment of communities.

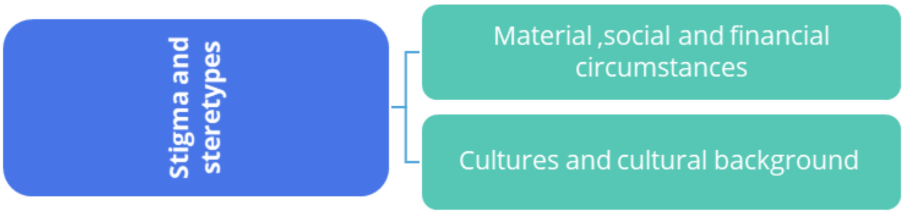

Figure 13 - Community disempowerment, stigmatisation and stereotypes

Social and environmental determinants of health should be considered within organisations, concerning the well-being, paying attention to housing, security, income and stability of patients, and the funding and policy environment in which the clinical practice is being developed. To recognise the environmental difficulties, changing organisational cultures and moving away from the so-called 'medical model' are facilitators of community empowerment that can be fostered from healthcare organisations: healthcare organisation can support communities in building 'structures' and in structural change through person-centred care, culturally-tailored attention or recognising the intergenerational effects of discrimination, the financial, social and cultural barriers that affect individuals and the necessity to share results and information with the community.

Concerning barriers and community's resources, the problems in accessing healthcare (insurance, fees, limited clinic resources, etc.), the job and housing insecurity, lack of rest time and vacation, financial hardship and problems directly concerning the neighbourhoods and infrastructures are critical for their empowerment, participation and, also, for the health outcomes of this particular population.

At the community level, facilitators for empowerment are activism, advocacy, symbolic elements and positive role models, and information, health literacy and identity, self-worth, pride, and reappropriation. To reduce the stigma and discrimination, valuing the communities and individuals' voices are factors that raise empowerment.

On the other hand, barriers may be related to cultural background and, then, power imbalance (e.g., medical model, physical impairment-centred approaches, lack of intercultural discourses for illnesses, alienating styles of communication, paternalism, biased information), problems in organising advocacy groups, disengagement in patients' groups and weak organisations of patients, separation of associations, poor comprehension of collaborative practices, or collective feelings of powerlessness. Stigma and stereotypes play an essential role in diminishing community empowerment. Issues considered at the intersectional level are the probable fear of authority, the stigma attributed to certain illnesses or disorders (leading to low or none social support, sense of worthless, non-disclosure, no visibility, misrepresentation...), the dismissiveness and negative assumptions in regards to poverty, ethnicity, substance use, mental issues, sexuality or gender performance, disempowerment and helplessness.

Ethnicity, sexuality and gender are considered separately in the table below: specific issues arose within the studies in regards to these three factors (presumed low proactivity, racial tension, biphobia, heterosexist claims, dismissal of women's health issues or attribution of female's physical claims to mental disorders, among others).

Partnerships between healthcare organisations and communities, including civil society organisations in touch with these communities, are vital for moving towards the current model and its intrinsically rooted problems. A vast range of stakeholders should be included, allowing participants to socialise, bonding and share a shared sense of identity; the mutual support groups and, even, peer-supported groups for health literacy can act as 'extended families' in particular for those in a situation of isolation (persons living alone, migrants without relatives, etc.). Community organisations, leaders, and patient advocates can enhance the prioritisation of community needs to tailor care to the current and actual needs of the groups targeted. Also, relatives, loved-ones and extended social network members (e.g., co-workers, colleagues, education centres, faith-based organisations) can be included.

Table 24 - Enhancers and barriers for communities' empowerment

Enhancers	Barriers
Organisational level	

To consider the social and environmental determinants of health - **social view** of health and wellbeing (ED16) (ED9) (EN02) (EN18) (EN19) - adequate social **housing** (EN02) (EN17) (EN18) (EN19) - **Funding** and **policy** environments (EN02) (EN19) - allocation of **health care funding** (EN02) (EN17) - better access to **income support** (EN02) - **security** and stability (EN17) 1. recognising **environmental difficulties** (EN17) 2. to change **organisational cultures** (EN02) 3. To move away from the **medical model** (ED16) (EN02) (EN10) - **Structure building** and structural change (EN02) (EN20) (EN28) - To **co-produce person-centred care** based on communities, families and patients' experiences (EN10) (EN14) - to discuss possible **anti-racist** approaches (EN02) - recognize the **inter-generational effects** of systemic and individual discrimination and racism (EN02) - recognise the dependency on **financial, organizational, and social or cultural** barriers (EN18) - To **share results** with communities and individuals studied/involved (EN28) - **Service [HCPs] education** (EN01)	
	Communities' resources
	- Healthcare access issues: o Problems in accessing healthcare (EN17) (EN24) (EN32)(EN39) o insurance issues (EN24)) EN32) (EN39) o fee-for-service system (EN39) o limiting clinic resources, such as production of evidence-based clinical guidelines (EN32) o curtailing health professional education and awareness (EN32) - no job security (CO08) (EN24) - Housing (EN24) (EN39) - no vacation time (CO08) - financial hardship (EN24) - Neighbourhoods issues o city master plan (EN17) o urban renewal (EN17) o economic displacement (EN17) o abandoned homes (EN17) o non-existent sidewalks (or those in need of repair (EN17) o few businesses geared toward healthy living (EN17) o many places of worship (EN17) o Minimal investing (EN17)

Communities, norms and values	
Community empowerment, groups' empowerment: - **Activism and advocacy** (ED9)(EM05)(EN01) (EN02) (EN10) (EN19) (EN20) (EN40) o Use of **symbolic elements** (ED9-LGBTIQ+) (EM05-men prostate cancer) (EM05-unity) o Endorsement to **positive gender models**– even it these are "gender-biased" or stereotypical (EM02-men); (EM05-men); (EM09-men) (EM17-older CALD women) (EN17-men) - To obtain/gain **information & health literacy** (ED9) (EM13)(EN01) (EN34) - Enhanced **identity and self-worth** (EM10) (EM16) (EM19) (EN34) - CALD cultural **pride and "reappropriation**"(EM09) (EM17)((EM19)) (EN34) o Use of culturally-tailored means (EM09) - Brotherhood (EM09) (EM10) (EN17 (EN34)) - Storytelling (EM09) - Older generations (EM09) - Small groups of men/women (EM09) (EM10) (EM17) (EN34) - Understanding of cultural views of the disease (EM17) - Verbal transmission, verbal relations (EM17) - To reduce the **stigma** (EM16) (EN19) (EN25) o To disseminate information to the general public by showing possitve examples of persons with a condition/disease/disorder/illness (EM16) o To provide accurate information to the general public overcoming stigma (EM16) (EN19) o To enhance the community engagement (EN19-LGBTIQ+) - Gaining **trust** (EM13) (EN10) (EN20) - value **voice and choice** (EM19) (EN02) - Participation in **counterhegemonic movements** raising the capacity for adquiring information (ED9) (EN19) - To **publicly disclose** the condition/disease/disorder/illness (EM16)	Cultures and cultural background: - Power imbalance o medical model (CO37) o physical impairment-based approach (CO37) o intimidating styles for "forcing" the treatment compliance (EN33) o Reducing the "patients' empowerment" to compliance, to meet the "good patient" role (EN42) o No accurate representation of **inter-cultural discourses of illness, diseases o disorders** (EM17) o Discriminatory or alienating styles of communication (EN02) (EN25) o Avoidance and lack of shared information (EN28) - navigating multiple identities while interacting within social and ecological contextual factors (ED9) - Biased health education including sex education (ED9) - Problems in organising advocacy groups: - Patient groups: o Disengagement (EM17) (EM19) ▪ Older women's disengagement in advocacy (EM17) ▪ Disengagement due to stigma in LGBTIQ+CALD (EN25) o Weak patients' organisation (EN39) o many groups remained separate and independent (EM05) o lack of long-term sustainability (EM05) o lack of solidarity between advocacy groups (EM05) - Providers-community relations o Difficulties in adhering to power-sharing, collaborative decision-making, equal voice and choice (EM19) (EN10) (EN17) (EN28) (EN39) o powerlessness (EM19) (EN17) (EN28) o Collaborative practices not understood (EM19) (EN10) (EN39) o Tokenistic approaches (EM19) (EN10) o Insufficient planning (EM19) (EN10) o reduced collective power and capacity to negotiate rewarding

	affiliations with professional organizations (EM05) o Passive attitudes (EM19) o passive resistant attitudes, deeply embedded in the current paradigm (EM19) o power dynamics and dominant-subordinate role structure (EM19) - Organisation of cultures and cultural change in clinical care; mission and vision (EN02) - Research and interaction: Priorities of the researched community are not considered (EN20) Stigma and stereotypes - Intersectional o Fear of authorities (EM09) o Stigma linked to a disease/illness/disorder ▪ Lack of social support and network; loose of previously existing networks (EM16) ▪ Worthless (EM16) ▪ nondisclosure create relative silence about respondents’ HIV-positive status, which allows the high HIV-related public and structural stigma within the Dutch society to remain existent (EM16) ▪ lack of visibility of campaigns (EM16) ▪ lack of representativeness or mis-represented collectives in communication campaigns (EM16) o dismissiveness, stereotyping and negative assumptions related to poverty, racism, substance use, mental illness, sexuality, gender performance (EN02) (EN19) o Stigma on poverty (EN24) o Disempowerment and alienation of marginalised groups (EN02) (EN17) o *well-deserved* mistrust (EN17, sic.) o helplessness, inability to break the chain (EN17) - Racial or ethnical stereotypes o Presumed low proactivity in African-American women (CO06) o sexual fetishization (ED9)

	o racially motivated objectification (ED9) o In education, lack of diversity (EN17) o Persistence of racial tension (EN17) o Poorer health outcomes (EN45) - LGBTIQ+ stereotypes and stigmas: o Biphobia; stigma (ED9) o heterosexist assumptions (ED9) o heteronormative structures (ED9) o conflicted between authenticity and safety (ED9) o education based on fear and shame (ED9) o Dangerous places and cities for the LGBTIQ+ (EM02) o conformity is socially policed (EN19) o It's threatening to be with a *feminine man* (EN19) o institutional stigma (EN19) o sinners, social exclusion based on faith organisations; isolated/excluded from their families (EN19) o Underengagment of Bangladeshi; Muslim; African (especially Sub Saharan/Horn of Africa/Afro Caribbean); - Gender stereotypes: o Dismissal of women's health problems (EM17) o Attribution of women's physical claims to mental health issues (EM17) o Women's disempowerment in interacting with HCPs (EM17) o Eastern European; South Asian (EN25)
Partnerships: organisations and communities	
- Involving a vast range of players (CO26) (EM19) (EN14) (EN20) o network support by allowing socializing and bonding (CO26) (ED8) (EM09) (EM10) (EM13) (EM15) (EM19)(EN01) (EN20) - Role of mutual support group "extended families" involving peers and friends for the CALD (EM04) (EM09) (EM10) o Peers, survivors; others who have been through the same thing (CO26) (ED8) (EM09) (EM10) (EM13) (EM15)(EN01)(EN10)(EN14) (EN20) (EN34) (EN40) o health institutions/workers (CO26) (EM17) (EM19) (EN01) (EN02) (EN14) (EN18) - community organizations (CO26) (EM08) (EM17) (EM19) (EN02) (EN20)	

○ community leaders(CO26) (EM05) (EM08) (EM17) (EN029)(EN17) (EN20) (EN45) ○ Patient advocates (CO08) (EM05)(EN01) (EN02) (EN10) (EN14) (EN40) ○ Community problem prioritization (EN01) (EN20) (EN45) - family members (CO26)(ED9) (EM04) (EM19) (EN14) ○ Relatives, wifes and partners of survivors (CO26) – gender aspect* ○ Parents (ED9) ○ Role of family and education acquired in prevention behaviours (ED9) - worksites; Job environment, employers and co-workers involved, supportive (CO08) (CO26) - education centres schools (CO26) - faith-based organisations (CO26) - media (CO26)	

Patients' autonomy and the disease living experience: individuals between empowerment, responsibility and guilt.

A sub-section on autonomy and living experience has been included due to its relevance in particularly vulnerable communities and individuals, in chronic disease and its links with previous sections, which give this analysis a transversal nature.

* * *

At the intrapersonal (patients) level, the sense of autonomy depends on the individual's perception of control, expressed through courage, independence and autonomy, self-care, and access to the information.

Table 25 - Control,autonomy and information

Control		
The *courage* construct	**Independency, autonomy and self-care abilities**	**Information**
- idea of *survivorship* (EM05) (EM06) (EM13) ○ Military metaphors (EM05) ○ given a new lease on life (EM06) ○ rejection of condescending attitudes, pity, etc. (EM13) ○ Spirituality and faith (EM06)	- Trust in their own personal strengths, in control (CO31)(ED16) (EM09) (EM11) (EM13) (EN37) ○ positive self-perception, self-pride (EM08) (EM09) (EM12) (EM13) (EM16) (EN37)(EN41) ○ Accountability ▪ responsible for their own care (CO02) (CO07) (CO08) ▪ Took ownership of the lifestyle changes	- Increasing the sense of agency by accessing to knowledge and **information** (CO01) (CO02) (CO08) (CO15) (ED14) (ED8) (EM10) (EM12) (EM13) (EN03 (EN41) - Availability of ICT (CO31) (EN03) - Research: ○ Reading academic literatur

- Advocating for their own care (CO08) (CO31) (EM16) - Becoming an activist (CO08) (EM16) - Capacity for effecting change in their organization and in the community (EM19)	needed for self-managing health (CO02) (CO09) (CO31) (ED16) (EN03) (EN03) (EN14) ▪ Self-managing the medications for taking them on a regular basis (CO09) (CO31) ▪ Conserving their culture's traditional remedies (EM08) ▪ Adjusting their own medications (CO19) (CO31) (EN14) ▪ Abandoning, reducing (by themselves) or stopping the treatment (CO09) (CO20) (EM11) ▪ Normalcy (minimisation, embeddedness of treatment burden) (CO20)((CO15) (CO31) ▪ Disclosure as liberation (EM16) ○ embodiment (ED8) (EM06) (EM08) (EM11) (EM16) ▪ cultural pride (EM08)(EM09) - Self-care ○ Coping abilities (CO15) (CO19) (CO35) (EM08) (EM12) (EN03) (EN03) (EN41) ○ rest and recovery (CO15) (EM06) (EN37) ○ Planning, organisational skills (CO15) (EM12) (EN03) ○ looking after themselves better (CO15) (EM06) (EM08) ○ Accept help (ED7) (EM06) (EM08) ○ Helping others (CO35) (EM06) (EM08) (EM13	e, clinical trials &c (CO08) (CO14) (EN41) ○ generic (CO31) (EN03) - Learning new things and skills (EN03) (EN37)

	○ intuition, ability to navigate the disease (EN06) ○ security (EN16) ○ commitment (EN16) ○ Assertiveness (EN16)	

At the patients' intrapersonal level, the disease's living experience has a significant importance at the moment of the diagnosis – arising emotions such as fear or terror and emotional coping mechanisms such as avoidance, even numbness, and hope or acceptance. **All these factors impact on the decision-making and the motivation for engaging in self-care and self-management**.

At the moment of the diagnosis, unpleasant emotions and, more specifically, fear, hopelessness, disappointment, anger or rage, impotence or confusion increase the vulnerability of the patients making particularly important the counselling and communication from the provider and the range of factors impacting on the sense of autonomy detailed above. Facing the diagnosis may imply to **renegotiate the self**, to develop the personal spirituality or faith (if any) or adverse outcomes in body image or self-stigma, as well as material circumstances, such as the loss of employment or career, isolation, financial problems or autonomy-related issues (e.g., inability to travel or drive by his/her own).

Living with the disease will suppose an increased sense of responsibility and accountability, being aware and committed; however, avoidance, again, powerlessness or guilt may undermine the lived experience of the person. Fear may lead to avoidance and, then, low or non-adherence, low engagement in social activities (i.e., reduced social support and increased isolation, factors related to poor self-management of chronic conditions in previous sections) and denial of the disease. On the other side, acceptance and hope could be present as well.

Feelings experienced at diagnosis are related to how these are communicated (face-to-face and at the patients' pace) and also the counselling (CO08)(EN02)(EN32)(EM16)(EN32). The diagnosis implies grief (CO06)(CO08)(CO26)(CO33) (ED14) (EM07) (EM08)(EM12)(EM15)(EM16)(EN01)(EN18)(EN29)(EN05) (EN18) (EN29), related to the shock, changes that should be undertaken, coping abilities and the possibility of death or severe physical impairment.

Table 26 - Feelings at the diagnosis and their impact on disease living experience

Unpleasant emotions/feelings at the moment of the diagnosis	Pleasant emotions/feelings at the moment of the diagnosis
- Fear ○ Fear of ▪ being labelled (CO06) (CO26)(EM16)(EN01)	- Acceptance (CO09) (ED14)(ED7) (EM06) - Hope (EN32)

• as being sick (CO26)(ED14)(ED8)(EM07)(EM15) (EM16)(EN05)(EN16) • overly needy (EM15) ▪ prognosis (CO08)(CO33) (ED14) (EM07) (EM08)(EM12)(EM15)(EN18)(EN29) ▪ recurrence (CO08) (ED8) ▪ consequences of meds (CO33)(EM07)(EN05) ▪ reliance on meds as constant reminder (EN05)(EN18)(EN29) ▪ loss of control (CO33)(EM12)(EN05)(EN18)(EN29) ▪ dying (CO33)(ED8)(EM08) ▪ discovery, receiving diagnosis (EN01) (EN05)(EN16)(EN24) ▪ losing freedom (EN05) (EN18) (EN29) o Avoidance ▪ Denial, avoidance of the disease itself (CO08) (CO09)(EM08)(EM11)(EM12)(EN01)(EN05)(EN24)(EN32)(EN42) ▪ Low or non-adherence (CO09) ▪ Lower engagement in social activities (EM16) ▪ disengagement (CO09) ▪ active substance abuse (CO09) ▪ It doesn't make sense to worry too much (EM08) ▪ Suicidality (EN37) o Shocked (CO08)(ED5)(EM08)(EN32)(EN33) o Scared (CO08) (ED14)(ED8)(EM07)(EM08)(EN01) o Threatened (CO33) (ED14)(EN01)(EN16)(EN24) o Numb, frozen (CO08) (CO09)(EN05) o Overwhelmed by exposure (CO33)(EM12) o Terrified (CO08) o Stunned (CO08) o Horrible (CO08) o Panic (EN33) - Hopelessness (EM07)(EM16)(EN02)(EN37) - Disappointed (EN37) - Betrayal (CO09) - Anger, rage (CO09) (ED14)(ED14)(EM04) - Impotence (ED14) - depression (ED14)(ED5) - misfortune (ED14)(EM07) - Worrisome (EN16) - Unacceptance (EN32) - Confused (EN35) - Vulnerable (EN35)	

General consequences – after the diagnosis - may imply renegotiating the self; radically changing assumptions about their own person (CO08) (ED14)(ED8)(EM06)(EM12)(EM15)(EN05)(EN15)(EN37). **Feelings experienced during the diagnosis and immediately after impact on the decision-making abilities and motivation** (EN33) (EN37) (EN42) and, then, in the **consequences** of the disease and health outcomes. The disease can also have an impact on the persons' material circumstance: loss of employment, gain isolation, financial problems, disabilities, or difficulties in driving or travelling appeared. All these impacts complicate even more a potentially previous situation of suboptimal social inclusion

Table 27 - Consequences of the disease in the patients' living experience

Positive consequences of the disease	Adverse consequences of the disease:

- Spirituality, fear-based coping (CO06) (CO09)(ED14)(EM06)(EM07)(EM08) - Destinity (CO06)(EM06)(EM07) - Opportunity to improve (ED14)(EM06) - enhanced self-esteem (CO08)	- Individuals' health and mental health: o body image (CO08)(ED8)(EM06)(EM08) ▪ I still don't feel beautiful (CO08) ▪ changes in body hormones (CO08) ▪ sexual function (CO08-women) (EM08-men) o Self-stigma (EM16)(EN05)(EN16) ▪ Socially unacceptable disease (EM16) ▪ Dirty disease (EN05) ▪ Binding disease (EN05) ▪ Pushy disease (EN05) ▪ Arrogant disease (EN05) ▪ present disease (EN05) ▪ master narratives of silence and isolation that surrounded breast cancer in the past, which is contrasted with openness and proactiveness in the present (EN16) - In the material circumstances o Employment (ED7) (EM12)(ED14)(EN37) ▪ End of career (EN41) o Isolation, separation from their social attachments (CO08)(EN05)(EN37) o Financial problems (ED7)(EM15)(EN37) o No ability to drive (EN37) o No ability to travel (EN37) o Disability (ED14)

* * *

Personality (EM07)(EM08) and **age**(CO11) seem to be significant determinants in self-management, as previously described. Linked to the factors as mentioned earlier, facilitators for living with the disease were **motivation, health literacy, awareness and commitment, ability to help others, empower peers, acceptance of the disease, embodiment, good self-management abilities, and goal-setting skills**. In parallel and in-line with the insights reflected in section 3 on Self-management, a sense of powerlessness, the tendency to catastrophising or avoiding (avoidance), guilt, and low social support are the most important barriers for living with the disease.

Table 28 - Facilitators and barriers of patients' autonomy

Facilitators:	Barriers:
- Positive attitude, motivated (EM08) - Health literacy; to educate themselves (ED14) (ED14)(ED16) - Being aware and committed o Being aware (CO02)(CO09) (CO31)(EM06)(ED7) ▪ Being concerned (EM06) ▪ Consequences for choices (ED7)	- Powerlessness (EM07)(EM16) o Low self-efficacy as a guilt-enhancer (EN36) o Lack of confidence for asking, fearing disturbing the doctor (EM11)(EM17)(EN42) o to apologize for explaining things "poorly" (EN36Low self-motivation (EM07) o Shame and stigma (EM16) o No sense of autonomy, claiming for destinity of religious figures (EM07) - tendency to avoidance (EN02)(EN36)(EN42) - Guilt

o To empower people (CO37)(ED7)(EM08)(EM16) ▪ Identification of survivors; symbolic value (EM05)(EM08) ▪ To gain social support (EM16) o Helping others (EM08) - Self-management (CO09)(CO31)(ED16) - Accountability for taking meds (CO09) o - Acceptance of the disease (ED14)(ED16) - Constellation of symptoms, embodied self-awareness, embodiment (CO31)(EM11) - Tangible behaviour change (CO35) (ED7) - Exemplarity (ED7)(EM08) - To preserve life and health (CO09)(EM11) - Goals setting (CO02)(EM02) o meeting milestones (EM02) o Taking responsibility and self-manage his/her disease improves adherence (CO02)	- guilt and anxiety about their work, domestic and social lives (CO15)(EM06)(EM07)(EM15)(EN37) - guilt for the illness (CO08)(EM07)(EN05)(EN37) o To feel guilt and punished: My diabetes is like my conscience who punishes me when I make a mistake (EN05) o For the diagnosis (EN37) o For the prognosis/development (EN37) o Considering that the disease was self-inflicted (EN37) - guilt for not meeting the normative expectations at social and/or community levels (ED9) (EM07)(EM15) o Inadequacy (ED9) o Disinterest (ED9) o Resentment (ED9) o Fear of being perceived as needy (EM15) o To feel guilt for violating church sanctity if they discussed their own disease with other church members (EM07) - guilt for depending on others (CO08)(EM15) o They are restricting others' lives/enjoyment (EN37) - Considering themselves as lazy (CO15)(ED8) - cannot give emotional support to others (EM06) - being accused of gaining secondary advantages (EM06) - being healthy and at lower risk than a loved one/relative (CO06) - for competing psychological demands (CO04) - To receive guilt provoking feedback o from health care providers (CO02)(EN02)(EN33) o from family (CO02)(EM06) o judgmental attitude (EN02) (EN33) o Barrier for the disclose or for seeking attention (CO02)(EN37) o Nagging (CO02)(EN33) o Coercion (CO02) o Shaming (CO02) - Catastrophising (EM07) - insufficient social support (EM06)

At the **interpersonal level**, **trust**, **information sharing**, and caring contribute to expressing the patients' autonomy. The act of caring for others or accepting others' care is an essential dimension of expressing autonomy at the interpersonal level.

Table 29 - Meso-level factors and macro-level determinants of patients' autonomy

Meso-level factors
- **Trust** o In persons/HCPs: ▪ Developing mutual trust over time (CO11) (ED14) (EM13-peers) (EN03) (EN11) ▪ Selecting an HCP trusted by the patient (CO11) (ED14) (EM06) (EM11) (EM17)

    - In means, techniques:
        - Availability of diagnostic tests and treatments (CO14) (ED14)
            - Screening as reassurance; "everything is all right" (CO14)
- Information
    - **Decision-making**
        - Active role in making decisions (CO01) (CO02) (CO08) (CO09) (CO11) (EM11) (EM17) (EN03) (EN11) (EN14)
        - Discussing (CO02) (CO08) (CO09) (CO11) (CO31) (EM11) (EM17) (EN11)
        - Integrating the patients' point of view (CO01) (CO02) (CO31) (ED14) (EN03)
        - Validation of their experience (CO15) (EM12) (EN03)
        - Impersonal language
            - With positive outcomes for the patient (CO13)
            - With negative outcomes (EM06) (EM08)
        - Focusing on options (CO13) (EN03)
        - Relationship patient-provider; emotional bonds (ED14) (EN03)
        - Disclosing non-adherence (CO20) (EM11)
        - Person-centred care (ED14) (EM12)
        - Patients able to show doubts (CO14) (EN11)
        -
        - Flexibility (CO33)
        - Holistic, focused on the patient as a whole (Person-centred care (ED14)
    - Providing the needed information tailored to the patient (CO14) (ED14) (EM12) (EM17) (EN03)
    - Expert patient as navigator (self, systems, processes) (CO20) (CO31)
    - Increasing visibilities of their condition (CO08)
- Care and caring of others
    - Social and familiar support (CO04) (CO08) (ED9) (EM08) (EM10) (EM13)
    - Accept help (ED7) (EM06) (EM08)
    - Helping others (CO35) (EM06) (EM08) (EM13
    - Sharing knowledge and information (CO23)(CO31)(CO35) (ED8) (EM08) (EM10)(EM13) (EN03)

Macro-level co-determinants

- **Social and environmental factors:**
    - Higher SES (CO11)
    - Job safety (EN37)

The interpersonal dimension has significant importance for their autonomy, the way in with the diagnosis is received and the pace, and the patient's information needs; during the disease course, the validation of the patients' experience also plays a role. Information needs at the moment of the diagnosis might be higher than expected by the clinician: patients may expect reassurance, practical insight and knowledge, planning tips, and they might raise a lot of questions. Also, anxious preoccupation, distress, to feel unequipped in terms of knowledge, or asking for sensitive information (e.g., about dying) might be present. All these elements should be taken into consideration by the provider.

Table 30 - Facilitators and barriers of patients' autonomy and providers' interaction

Facilitators	Barriers:
- Reassurance (CO06) (CO14) - practical knowledge (CO32)(EN32) - needed for planning (EN32) - lots of questions (EM12)	- Anxious preoccupation (CO13)(ED7)(EM12)(EN15) - Stress (CO14)(EM12)(EN15)(EN18) - patients' unequipped in terms of knowledge/info (EN05) - low knowledge about the condition by providers (EN32)need information about dying (CO33) - absence of body language (CO33)

Social and familiar support and the patient's support experience through providers or peers may be crucial for their individuals and their feelings of autonomy and control, both at the diagnosis stages and during the disease course. Isolation, low familiar support or financial hardships are critical as well.

Table 31 -Facilitators and barriers of patients' autonomy and social support system

Facilitators	Barriers:
- Support by loved-ones (CO08) (CO13) - Peers/providers emotional support (CO32)(CO33)(EM06)(EM08)(EM10) (EM12)(EN05) - Lister to peers' experiences (EM10) - Social status and SES (ED14) - Educational level (ED14)	- Lack of social understanding/validation (CO15)(ED8)(EM06)(EM15)(EN05)

In this case, the socio-economic situation (CO11) and social networks appeared as co-determinants (CO31) of the accountability and the abilities of the patient for "living with" the disease. Facilitators are the acceptance of help and support, health literacy and proactiveness in decision-making; in parallel, barriers are isolation, low relatives' supports or excessive delegation of responsibility in the HCP.

Table 32 Facilitators and barriers of patients' autonomy and psychosocial variables

Facilitators:	Barriers:
- To accept help and support (ED7-men)(EM06-women) (EM16) - To educate patients/individuals (CO37) (ED14) (ED16)(EM08) - To play an active role in decision-making (CO02) (CO04)(CO09)(ED14) ○ accurate and detailed information (ED14) ○ To choose not to follow the medical instructions; not to adhere (CO04)(CO09) ○ To disclose non-adherence (CO09) - To share decision-making with HCPs (EM11)	- Isolation (CO31)(EM16)(EN06) - Little help at home, low relatives' support (CO02) - Seeing the HCPs as the ultimate responsible for the final outcome of the treatment (EM11)

Two crucial and environmental factors (thus, macro-level factors able to tackled through policy-making) arose: to have a higher socio-economic status and job safety. Whilst there is not explicit mention, policies should consider the most critical impacts on individuals' lives in employment (ED7) (EM12)(ED14)(EN37) (EN41), disability(ED14), isolation (CO08)(EN05)(EN37) or financial issues (ED7)(EM15)(EN37).

Section 5. The role of IT tools and the Internet

The **Internet** has been characterised as an essential tool for patients; patients use online groups, forums and survivors' networks (CO08) (CO27) (CO31) (CO32) (CO33) (EM10) (EM12) (EN04) (EN37), specialised webs: general information from verified sources, scientific or clinical societies… (CO08) (CO27) (CO31) (ED9) (EM12) (EN15) and research articles (CO08) for increasing their health-literacy and building self-management abilities and skills. The Internet appears generically mentioned as well, as a primary source of information and communication (CO08) (EN04) (EN05) (EN32).

Thus, concerning **non-formal education**, health literacy programmes, online health literacy programmes find both barriers and facilitator, at the micro and meso-level. Online groups, forums and survivors' networks appeared in the studies (CO08) (CO27) (CO31) (CO32) (CO33) (EM10) (EM12) (EN04) (EN37). Firstly, online groups are considered as a valuable source of information and support (EN34)(CO33)(CO27). Secondly, when barriers to attend to face-to-face groups exist, it seems that online groups are a feasible option these can be useful for people living in rural areas while the access (CO33) while some participants may need or miss the face-to-face meetings and the vivid experience of connection (EM10). Lastly, online groups permitted to connect and contact with peers sharing experiences and helping to cope with the disease, offering relied, reducing their fears and helping to 'come to terms' with their diagnosis (CO27)

The role of IT, eHealth and mHealth in self-management

Within the meso-level, the role of mHealth and IT tools arose; organisational and community factors cross these technological aids; thus, are considered at meso-level whilst crossed by intrapersonal factors and macro-level cultural factors.

Concerning the advantages and disadvantages of IT tools, the table above summarises the main findings encountered in the studies sampled. On the one hand, IT tools make information accessible and easier to find, enhancing decision-making, preventing miscommunication, missed appointments and confusions. These tools are always available and have a potential for fostering the patients' autonomy and raising their competencies and awareness. IT tools can be adapted for behavioural change techniques, save time, money and human resources and can be used complementarily to face-to-face attention.

On the other hand, IT tools may also exacerbate the technological divide, might suppose a problematic factor concerning the patient-provider communication and the patients' informational demands, are lacking specific and truly personalised information, may show a lack of engagement and commitment, are impersonal and usually reinforce the sick model of patients.

Advantages	Disadvantages
- IT, Internet or information accessible and facilitated by the IT tools allows a better decision-making (CO31) (CO33) (CO38) (EN004) (EN37) (EN39) (EN42) - IT prevents from miscommunication, a missed appointment, confusion, frustration (CO31) (CO38) (EM12) (EN05) (EN39) (EN44) - Availability (CO33) (CO38) (EN04) (EN05) (EN37) (EN39) EN44 - IT empowers them (CO31) (CO38) (EM12) (EN39) (EN42) - Increases awareness; can change behaviours (CO38) (ED11) (EN37) (EN42) - Information is still there (CO33) (EN04) (EN05) - IT save time (CO31) (EN30) - IT save money (CO31) (EN04) - IT relieve the workload of HCPs (CO38) - Secondary gains for HCPs supporting/tele supporting: knowledge, skills, attitudes, social skills, insight… (ED11) - Patient-focused EN44	- Tech divide(CO32) (CO33) (EN01) (EN19) (EN37) - Lack of Internet access or poor access (CO32) (CO33) (EN01) (EN37) - Lack of devices (CO32) (EN01) - Views as a superfluous investment in very deprived or marginalised communities (EN19) - Problematic relation between HCPs and patients' habits and information demands (CO08) (CO27) (EN32) - HCPs are reluctants and/or advised not to go on the Internet (CO08)(EN32) - HCPs lacking clinical expertise in their disease [so turned to the Internet] (CO27) - Patients self-diagnosing (CO27) - Too generic; lack of needed specific indormation (EN35)(EN37) - Lack of engagement; Sleeping gym membership phenomenon (Accessing the first time and losing the interest) (CO32) - Impersonal (CO38) - Reinforces the sick model of patients (EN42) - Difficulties in establishing patient consultation or co-creation processes (EN44)

To sum up, the use of IT tools provides the feeling of control (CO31) and foster the patients' awareness and accountability (CO38), meanwhile relieving the workload of HCPs (CO38), but its successful implementation may depend on age (CO38), education (CO38) and material circumstances (CO38) (EN01) (CO08). The design of tools requires to appropriately tailor the software and applications to the users' circumstances and access to devices and connection (EN01) (CO32), culture and cultural customs (EN35) and preassumptions concerning the use of applications for health or not (CO32), considering as well that IT tools may be unsuitable for patients (CO38) or not engaging enough leading to the reality of the "sleeping gym membership" phenomenon (CO32)

IT tools' role in decision making

IT tools may also have a positive impact on decision making from both sides: patients, by allowing them more active participation in their (own) healthcare and treatment decisions (CO31), to research into specific information and research results (CO08), and to cross the healthcare services received by a patient at different clinics (CO31), and professionals, through built-in algorithms supporting the decision making (EN39).

IT tools and co-design, co-creation and co-production

Firstly, patients demand to foster the co-creation and the stakeholders' consultation for developing IT tools and services (CO31) (CO32) (EN30) (EN39) (EN42) (EN44) to ensure their relevance (CO32) (EN44), utility (CO31) (CO32) (EN30) (EN44) and user-friendliness (EN30) (EN34) (EN39) (EN42) (EN44). Also, data security and transparency (CO32) (EN39) (EN44) are mentioned. The studies have shown a demand by patients, consisting of a list of realisable or recommended websites (CO08) (CO27) (EN15), as well as direct communication via email or messages (CO27) (CO31) (EN05). Attractive services for patients, mentioned, are task management apps and reminder systems (CO31) (CO38) and medication management apps (CO31), but also training on seeking information on the Internet (CO27).

Preferences showed by patients are electronic format (CO23) (CO31) (EN05) (EN34), multidevice (CO31) (EN05) (EN30) (EN37), accessible and intuitive ('easy') interfaces, user-friendly and understandable (EN30) (EN34) (EN42), interactive materials (CO23) (EN34), to have all information in one place (CO31) and to have to read less text (CO23), while it may depend on each target.

SYNTHESIS AND DISCUSSION

This chapter comprises the synthesis and the discussion around the studies and their analysis and results. The sections follow the same order as reflected in the analysis and results, thus:

- Communication and counselling
- Health Literacy
- Adherence, compliance, self-management, and decision-making
- Empowerment and empowered communities
- The role of IT tools and the Internet

Lastly, a specific section on Strengths and limitations is included.

The discussion as a whole considered the socio-ecological model and frames the results and the literature within the social, cultural, economic and environmental circumstances and determinants of both health and healthcare as institution and as a process.

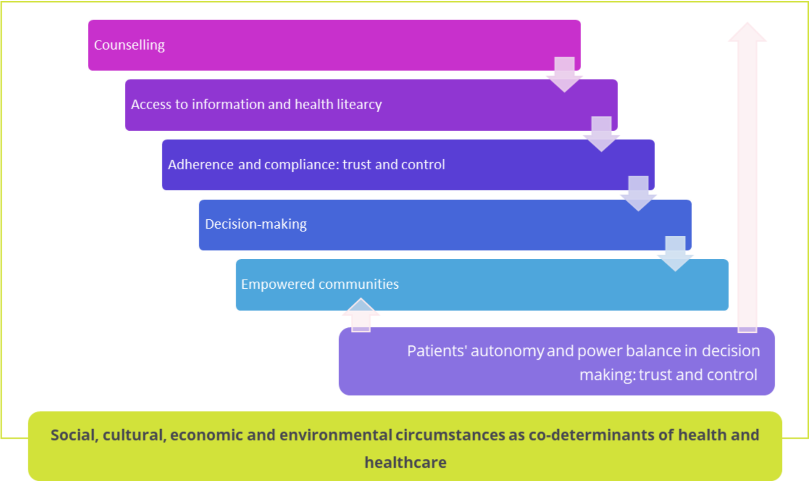

Figure 14 - Relations between themes and processes

Results have shown a relation between (i) counselling and access to information, health literacy and health education programmes and (ii) decision-making, involving the patients' proactiveness and active role in joint decisions but also the empowerment of higher vulnerable communities and their ability to modify structural and systemic conditions – at least, to some extent. Empowerment is directly related to policy-making, advocacy, and alliances. These can be an essential co-determinant of the patients' autonomy and the power balance in the medical consultation, impacting the counselling, self-management, and active role in decision-making. All these relations will be further explored and analysed in this chapter.

Section 1. Communication and counselling

To summarise and synthesis the results, the micro-level, meso-level and macro-level factors should be interpreted in light of co-determinants and intersectional issues. Co-determinants found in the examined papers, able to impact the counselling communication are literacy, individuals' self-efficacy (mostly, patients but also providers' self-efficacy), gender and sex, race and culture, material deprivation, age, physical and/or cognitive functions and the macro-scale policies able to determine and decide on care models (e.g., integrated care or active/proactive policies fostering the continuity of care for chronic care.

While factors should be better represented as a spiral, reflecting how micro, meso and macrolevel factors constantly impact each other's, figure 15 below chooses the pyramid presentation aimed at simplifying the exposition of factors and how changes on the bottom can be transferred for producing significant improvements at meso and microlevel as well.

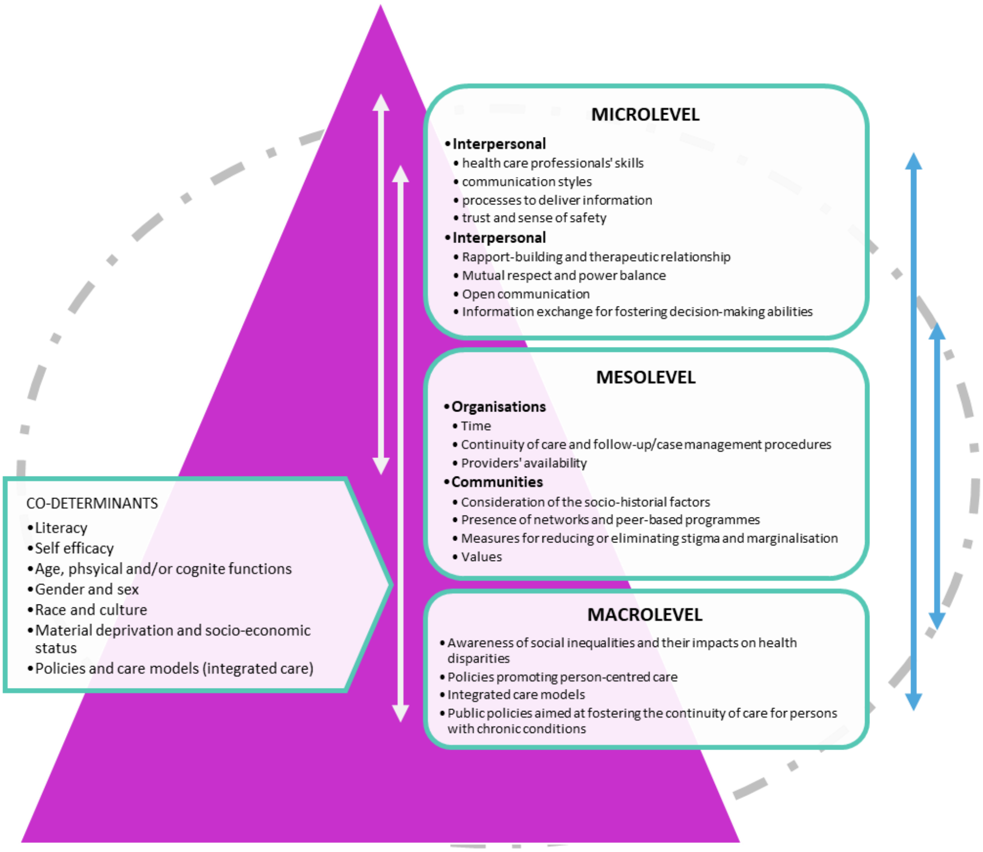

Figure 15 - Factors and co-determinants impacting on patients-providers communication and the counselling process

The discussion is organised into two categories, informational exchange and relational development (Hesse and Rauscher 2018). Firstly, some considerations about the amount and quality of the information and their role in the counselling are discussed. Secondly, the relational aspect is addressed by debating how the humanisation of care and communication styles may impact patient-provider communication. However, it should be noticed that the communication style and the relational dimension are intrinsically related: the relationship involves dominance-control, emotional arousal, self-reflection, etc. The relational dimension also depends on the HCP's communication competence and communication efficiency; both contribute to establishing a positive, negative, even neutral, relationship with the HCP/HCPs. (Hesse and Rauscher 2018). Then, the intersectional aspects are also analysed (racialisation, CALD communities, gender, age, abilities, etc.) and the organisational aspects that may be involved and have a considerable influence in the relationships generated and the knowledge exchange.

Amount and quality of the information and its relationship with the patients' empowerment

There is a link between the **information** – particularly its amount and quality - and empowerment highlighted throughout the studies. For instance, information and empowerment may be linked through having all needed information available or, on the contrary, the lack or excess of information might generate, in the patient, powerlessness and. Information is relevant in patients' autonomy and decision-making; however, relational aspects are inter-linked to informational exchange; e.g., a **trusty** relationship also allows patients to share sufficient information in a safe environment and make an informed decision.

Firstly, the amount and type of information should be considered. An inadequate amount of information could be overwhelming for some patients; moreover, some patients might have, autonomously, a lack of desire for information. It seems that lower literacy and lower self-efficacy may be related. In-Aligned with the studies, research showed that patients preferring a more passive role, being told what to do, or rejecting to receive information showing a preference for happy talk also may make problematic the decision-making process also the perception that there are "right" and "wrong" decisions or options is a barrier for communicating and for making a decision (Joseph-Williams, Elwyn, and Edwards 2014); the relation between communication and decision-making underlie these themes as a whole. In fact, the stigmatisation of *complex* patients (difficult, “over-informed”, or non-compliant) and lack of mutual understanding or integration of a more horizontal/balanced view of the therapeutic relationship between the GP and the patient is a barrier to communication (for instance, it appears in CO19 as well as in the literature (Joseph-Williams, Elwyn, and Edwards 2014).

The traditionally passive role involves low engagement in decision-making and undervaluing their experiential knowledge and the patients' health literacy: patients need to be reinforced and supported for considering themselves as capable of understanding information, options and for making complex decisions (Joseph-Williams, Elwyn, and Edwards 2014; Trappes-Lomax 2016).

Information may also be seemed as **insufficient** due to a **timely** response or due to the time to provide the needed information. **Vague** explanations are given to the patient also appears linked to a lack of information and the assumption of a passive role expected from patients. **As it has been previously introduced, decision-making and information availability are intrinsically interrelated**: this condition might be ignored or overlooked by HCPs. In fact, patients might feel numb and anxious about making decisions. The use of unclear terms, technical **jargon** and specialised terms are barriers.

The **lack of clear information** is frequently reported as problematic by patients , in particular when referring to side effects or the duration of the treatment. The attention to the **psychological impact** is also insufficient, and, in fact, the lack of info leads to confusion and frustration. Besides, and again in-line with the literature, it seems that chronic diseases may receive less frequency and direct care than acute conditions (Trappes-Lomax, 2016; Frost, 2015).

The emotional intelligence of providers and patients, improved communication competencies, empathy, and trust are associated with the patient's clinical competence; attentive and sympathetic HCPs obtain more information and have more opportunities for patient-centred care. (Hesse and Rauscher 2018; Trappes-Lomax 2016) As CO29 recognises, "there is some concrete overlap between the dimensions of communication and doctor-patient relation".

Detailed information and accurate knowledge about the **prognosis** might be lacking and noticed by chronic patients. Lack of rigour and up-to-date approach, even correct and **evidence-based** data, also appears; besides, a perceived or actual lack of knowledge about the different roles (e.g., surgeons and GPs) can also be found from the side of the patient. Moreover, patients might distrust GPs - mostly when compared with "specialists. Professional identities and interactions between professionals' treats and caring roles appear (e.g., nurses and GPs, GPs and specialists)

Communication styles and relational aspect

The amount of information provided and the communication style are two co-determinants in bidirectional communication, requiring trust, autonomy and the appropriate affection for disclosing the required information sincerely, planning the treatments and making decisions. Results and findings are consistent with the literature and also reflect an inter-relation with decision-making. This section discussed the role of harsh authoritarian and paternalistic communication styles.

On the one side, **hard-hitting confrontation, harsh authoritarian styles, or the direct use of coercion for forcing a behavioural change or trying to enhance the patients' adherence are analysed**. Patients may feel humiliated, distressed, agitated and perceive a lack of connection between the information perceived and their own universe of meanings. The **pathologization** of patients, accusing them, failing in asking questions or in noticing what is happening with patients led them to feel **intimidated**, offended, nullified or just misunderstood

Insensitive expressions, lack of abilities for communicating bad news or challenging diagnosis and impersonal communication 'restricted to facts', **while not necessarily and intentionally harsh**, might be received with shock. Time constraints again might worsen the communication and cause anxiety and emotional suffering in patients.

Authoritarian styles, dismissal, domination of the encounter by the HCP, do not adhere or met to the patients' therapeutic goals and priorities, or to present treatment options in a biased way are barriers for communication and necessary burdens for patients' involvement and decision-making (Joseph-Williams, Elwyn, and Edwards 2014). Unwillingness to discuss health information obtained by the patients, dismissal, paired with rushed communications, appear repeatedly and, interestingly, the lack of perceived interest by the provider drives patients to search for information on the Internet.

Also, some doctors might fail in offering alternatives, do not recognise the patient's role/autonomy, and reject all the patients' questions, suggestions, or decisions. Harsh communication may be verbal or non-verbal: for instance, "*rolling of the eyes,* *scoffing, and shaking the head*" (EN09) are, themselves, attitudes that dismiss the patient experience, problems and overlook the emotional impact of the good and bad rapport.

Coercion for raising awareness may be useful but also leads to avoidance strategies and inhibited dialogue. Poor attunement between patients and HCPs also impacts adherence: patients might want to "escape" (e.g., in EN05), patients may reflect their views in absolute terms (e.g., *I hate the controls* in EN05) and, sometimes, avoidance and angriness. **Disrespectful attitudes** appear linked to infantilization.

The patients' considerations about harsh or hard-hitting confrontational styles, **authoritarian** styles, even coercion can impact diversely depending on the background (e.g., in CO09, higher-educated patients were much more critical). Also, the disempowerment of previously empowered patients seems to have a very different effect on the counselling than the unempowerment (Edwards, Davies, and Edwards 2009).

'Power' refers to the patients' capacity for making decisions through participating in the medical encounters, having or acquiring the necessary skills for fostering their participation, enhancing the patients' self-efficacy and sense of autonomy, acquire information and medical knowledge and using all these factors during the communication intercourse, within the therapeutic relationship in the context the decision-making process/es (Joseph-Williams, Elwyn, and Edwards 2014).

Power imbalances are also reflected in the form of "covert contracts": the patient should be a good patient, a "normal patient": goodness and normality are jointly taken. Patients should be passive and compliant and cannot be actively involved. Then, patients are separated from their own previous experience, social environment, cultural settings, media, literacy, and roles. Knowledge " provision, acquisition, and expectation to contribute personal preferences are done in the context of a power imbalance between clinicians and patients". Likewise, passiveness of the patient can be presumed by HCPs (Joseph-Williams, Elwyn, and Edwards 2014)

Person-centred care improves the understanding of the importance of taking an active role in our own health, our health literacy, and the knowledge, skills, and competencies required for participating actively in self-management and decision-making processes while improving self-care and health-promoting behaviours (Simmons et al. 2014).

The lack of emotional support is noticed throughout the research; the **deprivation of affection** or empathy perceived by the patient- and it is imperative in long-term, chronic conditions - leads to less security, loneliness, even more pain and sleep issues (Hesse and Rauscher 2018). Patients may perceive that GPs are only sticking to routines and protocols, and consequently, it drives **dissatisfaction**; it also may involve disengagement, depending on other factors, such as the prognosis, personality or social support. As EN04 explains, **harsh or problematic encounters may produce feelings of loss of control in patients and, consequently, inhibited dialogue or a sense of helplessness**.

On the other hand, Paternalism may also be crossed by socio-economic-cultural issues but mainly refers to the power imbalance and the therapeutic relationship. Undermining the patients' autonomy by limiting the information far beyond from the mere prudence or direct and rude comments about patients, jointly with challenging the validity and trying to shock them are just mere examples of power imbalance in the medical consultation and how it drives to difficulties in the communication (for some examples, EN32 or EN33 can be consulted).

To sum up, the "partnership" is redefined in the terms that the power imbalance and the traditional framework of interaction allow: so, "self-management" is redefined as compliance, "empowerment" is re-interpreted as an individual sense of autonomy, and the community seems to be irrelevant; in this context, it seems that "partnership" with the patient is to have a relationship with some individuals and/or associations, rather than mutual learning and collaboration. Even the possibility of real collaboration can be dismissed by the HCPs involved.

The most important trend observed in paternalistic communication seems to be the infantilization of patients: Some patients referred to be treated "*like a child*" and similar expressions referring to childhood (CO02, CO09, EN33, EM04) or to be warned about searching for information on the Internet and their supposed ability to process and analyse all this information (Trappes-Lomax, 2016; Edwards et al, 2009). Patients might be systematically overruled, and their abilities for making decisions are questioned. Some others explained how the paternalistic attitude was notorious (e.g., in CO20, the expertise of patients is dismissed; in CO27, a patient explained how some experts provide evidence for supporting decision-making meanwhile others do not want to discuss treatments and decisions; or, in EN23, the access to rescue pack is restricted to those perceived as "more capable" by the physician).

Organisational aspects impacting the information exchange

Key organisational aspects that impact the information exchange are the **time** devoted to the consultation, the **availability** of HCPs and the **roles** that they play within the institutions; also, **continuity of care** – and the rapport building process required for being established - and other **macro-level** decisions (e.g., policies sustaining an integrated care model) are also relevant.

Organisational issues may be at the local level or determined by policies and regulations; some of the most important are the service fragmentation, over-specialisation, issues in internal communication, lack of continuity, or pressures – even organisational policies - to reduce consultation time and to increase the 'cost-effectiveness' (Trappes-Lomax, 2016; Frost, 2015; Joseph-Williams et al., 2014)**-**

Time constraints and the time provided for consultancies appears in all studies analysed. Time constraints affect both sides: patients and HCPs. HCP should always consider the importance of **rapport building in order to obtain complete (reliable) information**; it applies, in particular, to cross-cultural communication and also with highly stigmatised groups (sex workers, HIV patients or persons with severe mental diagnosis).

The **availability of the HCP** is valued while it also may raise ethical and limit-related issues.

The **role of nurses seems to be differentiated**[11] by patients: warmth - it is being hypothesised that it may be gender-related - and, sometimes, more time to discuss about changes, problems and challenges; it seems that their role is also related to raising the motivation/awareness. From a more "managerial" or "administrative" point of view, to seek for patients' feedback in regards the quality **evaluation** and related aspects is positively valued.

The **continuity of care and professionals' internal coordination** is also mentioned explicitly in various studies[12] revised. **Follow-up during the treatment**

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[11] Specific examples can be found in those studies: (CO01,CO20, CO36, EN06, EN15, EM17)

[12] CO1, CO08, CO23CO32, EN38

and the transition and continuity of care seems to be important and repeatedly appears during the whole research. **Trust** seems to be a bidirectional quality that should be 'gained'; it is not given or implicit and it is dependent on the reactions of HCPs - for instance, in sharing their opinions or "discoveries" - or, even, peer groups).

Continuity of care is also related to **integrated care**[13] and, indirectly, **to person-centred care**[14]**.** In fact, evidence suggests that poor continuity of care and **integration of healthcare and social care services** suppose also a barrier for the communication, the inter-personal therapeutic relation and the informed decision-making (Joseph-Williams, Elwyn, and Edwards 2014). **Person-centred care should be also aware of the cultural issues** that may suppose a barrier for taking part in diagnostic processes, screenings or undermine the rapport. **Person-centred care provides a personalised frame**. Thus, a coordinated, strategic approach is merging predictive, preventive and participatory care. It can prevent high-risk behaviours and foster the patients' knowledge, confidence, skills, and pro-health behaviours (Simmons et al. 2014).

Considering the intersections in co-determinants examined, and after revising all studies and the literature cited, this dissertation proposes the term Critical Clinical Practice, which jointly considers the safety, awareness on power imbalances, social determinants of health – and education - , and the assumptions that may underline the traditional clinical practices, therapeutic relationships and counselling. The CCP-aware practitioner provides validation to highly-vulnerable or socially excluded patients' experiences and emotions, is aware of power differences, provides a safe environment, leads to joint decision-making, and tries to act under a "horizontal" perspective while acknowledging that the power imbalance is not avoidable at all. The CCP assumes that imbalances are social, economic and culturally determined and to be aware and concerned about the challenge and problems that these may suppose is the only way for reducing or mitigating its adverse impacts on patients.

In practice, it means that practitioners and HCPs should analyse internally, inter-personal and organisational levels how the power imbalances are present in their quotidian activity: it needs the commitment and awareness of the staff as a whole,

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[13] CO08, EN38

[14] CO01, CO02, CO08, CO29, CO33, EN02, EN16, EN24, EN36, ED14, EN32, EN36, EN40

but also the involvement of the wider community – in particular if treating patients with highly stigmatised conditions (HIV/AIDS, mental health issues, STIs, etc.).

Section 2. Health Literacy

Nutbeam integrates knowledge, skills and self-management of health within the definition of health literacy as cited by Edwards (2009); also distinguishes between three levels: functional, interactive and critical health literacy further detailed in the section on the *Conceptual Framework*.

Higher levels of literacy, education and self-efficacy and an appropriate access to the information facilitate the access to self-directed health education, also supported, at interpersonal level, by peers (friends, family), patients' advocates, experts and healthcare professionals. Integrated and easy-to-navigate healthcare systems facilitate the acquisition of health education and improve individuals' access to reliable information; these systems should interact coherently and consistently with cultures and customs, stakeholders, and communities reached. **Socio-cultural inequalities and economic disparities suppose a major barrier for health literacy and self-directed education.**

At the collective level, the acquisition of health literacy by deprived or discriminated persons and groups through programmes and mutual support groups, including associations, faces a challenging scenario in two stages: the recruitment and the implementation of the intervention.

* * *

This section of the discussion further analyses and re-interprets the outcomes shown in the section on Results; it is divided into three different sub-sections: health literacy and self-directed health education, recruitment of health programmes and interventions and implementation of these programmes, thus following the same structure used for the analysis of the reviewed studies.

Individual health literacy and self-directed health education

Self-directed health education and, so, health literacy presents a challenging frame of analysis, being mediated by several co-determinants and factors, as previously analysed in the section on Results.

This sub-section further analyses the health self-directed education, considering it in-light the individuals' subjective value, the acquisition of the information and the contextual determinants – social but not restricted to them – that mediate the ability and the access as well as the perceived value of the health literacy.

The value of the information

Firstly, individuals' value and, sometimes, groups to the information and, consequently, the value attributed to the acquisition of health literacy is analysed.

Health literacy is intrinsically related to knowledge about medicine, self-management and, in general terms, health-related behaviours. At the interpersonal level, knowledge is viewed as autonomy and control, a determinant of the patient's decision-making capacity, a mediator for *embodiment*, and a powerful motivator for change.

At the interpersonal level, knowledge and information reinforce peers' empowerment, is a vehicle for overcoming the stigma and an enabler for further discussions with the general wider society or the immediate social environment.

The link between he**alth literacy, information or knowledge and the ability to make decisions** remains throughout the revision and repeatedly appears across the studies; the **sense of autonomy and the locus of control** play a major role in decision making and, as it has been showing, in the willingness of increasing the individuals' health literacy.

Contrary to these more pro-active approaches, there may be a more traditional approach: some patients would prefer to feel guided, then the information is directly delivered by HCPs. From an **ethical** point of view, information should be suited to the patient's health literacy, curiosity and must be accurate and precise.

Again, and similarly to the previous chapter on counselling and patient-provider communication, **the lack of information available interferes with the decision-makin**g. Patients may be discouraged by providers for looking for information and health literacy by themselves.

In regards to the HCPs, more guidelines and practical information is required for avoiding ineffective repeating measures (EN25, EN34) and improve the quality of the information (EN32)

Sources for acquiring information are various. **Friends** and the **Internet** are key resources for obtaining the information, particularly if the information is not understandable or not enough and adapted to the patients' demands. Mass media, DVDs or videos and books are also mentioned. **Specialists** and experts - through the second opinion - are another via for obtaining information if it is scarce. Sometimes, the online or face-to-face patients' groups provide the evidence needed for looking for a second opinion (Hu 2015; Lee and Kam 2015; M. N. Robinson et al. 2014; Schiavo 2014). The **information format** - graphics, charts, pictures and visual formats; some patients may also expect written information such as brochures or leaflets.

Acquisition of information in the community: peers and programmes

The information can be acquired in the community; this section revises the acquisition of health literacy in patients' associations and education programmes and mutual support groups. While participation in programmes for promoting health literacy, prevention or groups of peers and survivors is extensively discussed, these are contemplated as long as peers and communities are used as a regular information source from the individual's point of view. Then, the section also revises which sites are relevant for the access to health-related information and how this access in the community should be modulated for the CALD persons.

To provide information reinforces peers' empowerment

Sometimes, **patients' education programmes** appear. On other occasions, people demand to have experts within the health education groups. The collective knowledge sharing may increase the knowledge and the patients' skill. **Associations** are also a valuable source of information as well as survivors and **mutual support groups**. Online support groups are included and explicitly mentioned as been positive sources of information, further *described Section 5. The role of IT tools and the Internet*.

Other relevant sites in the community, and depending on each target group, could be meeting points and, moreover, sources of valuable information: local business such as barbershop or pubs, health care infrastructures, churches or fraternal organisations. Barbershops are a culturally appropriate venue for disseminating health education materials in both print and media formats and may also be appropriate for recruiting users and analysed in the literature (Luque, Ross, and Gwede 2014). Similarly to other community places and key persons, barbers can increase knowledge and promote health-positive behaviours as peers, but more research is needed in this regard.

For CALD communities, interpreters and culturally tailored concepts are crucial: they may show a preference for visual aids and graphic information highlighting the value of storytelling techniques, information in their mother tongue, or alternative/adapted programmes.

Contextual determinants for accessing information

There are some important barriers in the accessibility of the information and the self-directed health literacy, such as the **isolation and the lack of social networks**, the **racialisation** and how it impacts the disparity in **health information access** and **gender issues**; for instance, masculinity has an impact on the acquisition of information on screening or treatment of prostate cancer and the femininity, ethnicity and age and seem to suppose a challenge for navigating the healthcare system

Collective health literacy: programmes and interventions in health education

This section considers, separately, the recruitment and the conduction (implementation) of health education programmes, interventions and mutual support groups, as long as these both phases should be separately analysed and planned in real-life settings. While recruitment and retainment share some elements, the moment and phase in which each element should be applied may differ.

Recruitment of persons for health literacy and health education programmes

The recruitment should consider the material and economic circumstances of individuals and communities, the individuals' goals and motivations, how these are mediated by cultural factors that may undermine the recruitment, and how each person's personality and emotional factors should be considered when designing the recruitment campaigns. The trust in the recruiter must be taken into account, particularly when trying to attract hard-to-reach populations, to diminish the access barriers and the distrust in the researcher or public health authorities and officers involved in the programme.

* * *

Costs and expectations associated with the health education programme should be clarified since the beginning and it would be needed to obtain as much support as possible from community leaders, associations and civil society players and trusted services (faith centres, sororities and fraternities, social centres, health or social services, etc.). At this stage, mapping community places and actors helps design and fine-tune a robust and effective recruitment strategy. However, considering the role that material circumstances play even during the recruitment, to promote and support, through policy-making and advocacy, the dedication of resources and the design of policies aimed at reducing social inequalities and economic deprivation, stigma and discrimination are critical at medium and long-term, for ensuring feasible and cost-efficient recruitment.

There is a range of conditions that should be carefully assessed during the design and the execution of the health education programme or the launch of a mutual support group; to design and promote a fun, attractive (e.g., an opportunity to socialise) or relevant for the community is a critical first step – then, consultation even co-creation may be needed. Important factors are trust in the recruiter or the group/institution recruiting, the sense of community that the programme can provide, free or very low-cost, to pay for participating, or the active support of community stakeholders and leadership, as well as CSOs. The presence of health professionals may be attractive. Costs, travel times, connectivity issues, incompatibility with job schedules or caregiving obligations and other complex socio-demographic issues related to social class, job and socio-economic resources should be taken into account. Besides, considering socio-cultural factors (e.g., gender, cultures, norms and customs, among others) is essential when trying to engage particularly vulnerable individuals[15] , discriminated groups or communities at risk of exclusion. Lastly, free car parking or public transport vouchers may be useful resources for increasing the success rates.

Literature offers some insight into recruitment sites as well as processes. A systematic review interestingly analysed different recruitment types: social marketing, community outreach, through the healthcare system, and referrals. Social marketing included mass mailing, mass telephone calls, and the use of media (newspapers, flyers, radio, TV, posters, etc.); the community outreach involved faith-based organisations, community leaderships and organisations, presentations and meetings, community events, health screenings in the community or door-to-door. Healthcare system was also utilised through using HCPs as multipliers and referrals; lastly, referrals in the immediate social environment was used (friends, families, employees and co-workers, etc.)(UyBico, Pavel, and Gross 2007)

However, and considering the social marketing techniques, snowball sampling and recruitment seems to be far more effective than social media engagement in vulnerable populations (Chambers, Bliss, and Rambur 2020). Likewise, participants' trust should be considered by providing full, complete information about the research process and the risks to participation (at social, physical or psychological risks), also integrating the persons' resources constraints (Ellard-Gray et al. 2015)

Implementation of health education and health literacy programmes

This section revises the implementation of health education and health literacy programmes, including mutual support groups. The engagement in health literacy seems to be related to decision-making, the use and acquisition of information from

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[15] being very important to consider the potential emotional vulnerability, depending on the topics addressed by the programme

the Internet, and the sense of autonomy. It is probably due to its link to health literacy and acquisition of information, as discussed below.

Regarding the implementation, the crucial challenge is to engage the individuals and retain them during the whole intervention; the engagement is also mediated by economic circumstances, priorities and goals of each participant, culture and social environment, personality and emotional factors, and physical health. To co-produce sustainable groups, able to provide a safe environment, joining together similar persons able to build together a sense of identity and generate an environment favourable to mutual learning and exchange of knowledge and experiences is the most crucial factor for the engagement during the intervention and for generating a sustainable structure after it ends. Materials, resources and modes for delivering the programme (e.g., online or face-to-face) should be adapted considering the targeted population/s. **Then, the engagement potential appears closely linked to community empowerment: the potential for advocacy, group cohesion, and representativeness appeared as determinants for fostering the participants' retainment and involvement.**

* * *

The programmes' expectations and nature should be clear, in particular depending on the culture and the traditions, and how these modulate the adoption or reception of more passive or active methods; for instance, in ED2, cardiac rehabilitation is compared with Expert Patient Programme (EPP). The rehabilitation, led by professionals, was linked with the traditional "instruction", while the EPP appeared related to "discussion" and active learning methods – regardless of contents and the existing overlap between both interventions**. It is hypothesised that mutual support groups (further analysed below) are linked to validation between peers: this validation comes in mutual understanding, meeting persons with similar experiences and background (social, cultural and economic)**. The validation also means meeting emotional needs in a safe environment, focusing on everyday struggles and quotidian health and disease self-management challenges.

Well-delivered and **appropriate** information is a powerful motivator for change. Having enough information determines the decision-making capacity of the patient. Health education programmes can also support the self-directed, informal health education of individuals involved fostering their competencies for acquiring and analysing information.

In general, the support group (peer-based or led by professionals) also offer a non-judgemental environment among persons with similar backgrounds and experiences. The main appealing characteristics are presence (for face-to-face groups), discussion or support, being a valuable source of information and emotional rapport for the participants, who consider that the group enhance their coping skills. **Peer-based groups are also a valuable tool for promoting behavioural change** towards healthier habits and routines. The strengths are the capacity of learning from each other, to set goals and implement changes together. If the groups are led or participated by HCPs, nurses' educational role may be reinforced by patient associations. The support from HCPs is sometimes also a facilitator: HCPs' considerations may play a key role for some patients involved in peer-based training: the participation of HCPs can be a success factor. In addition, peers leading groups might have seemed like a direct link to HCPs. The multiplying potential can be considered: the patients' participation in groups also impacts the social and family environment.

Most important, Information is reinforcing peer empowerment. **It is important to let patients develop the skills and solutions for facing their own challenges, including them in the healthcare process, too** (Amann, Zanini, and Rubinelli 2016).

In groups, empathy between members is vital, and sharing experiences provided a confirmation of normality. The potential for lobbying and advocacy are essential facilitators, as well as cohesion and representativeness.

There are cultural, religious, social, ethnic, gendered, sexuality-related, age-related circumstances or dimensions that should be envisaged and considered when conforming to formal peer-based groups (Beales and Wilson 2015). Revised studies showed that culturally tailored means might be required, also considering to gender-tailor the programme or the structure of the intervention itself (e.g., in regards the masculinity, the focus on job/family 'obligations' or the brotherhood can be helpful; it seems that in parallel, sisterhood and sharing of experiences are useful in feminised groups).

To see results is a powerful motivator. Other facilitators are to have involved already motivated individuals, individuals that showed previous interest in the topic or, in general, in health or self-management, whilst it may bias the results (ED15; (Dale, Williams, and Bowyer 2012)).

The **adaptation and flexibility** of the programme are crucial for ensuring retainment while cultivating the telos. An internal dynamic and sense of power balance is required for sustaining these groups (ED10, ED2, ED4, EM05, EM15, EN02, EN19, EN34): Smaller groups (6-10 persons) would work better than bigger ones in building cohesiveness (ED4). Lastly, **safe places** are a crucial consideration for implementing sustainable interventions for hard-to-reach and/or highly stigmatised populations.

Peer-based health education programmes and mutual support groups

Particular attention should be paid to peer-support and peer-based groups; several programmes, such as CDSMP or the EPP use this modality. Also, other similar interventions and non-structured interventions such as mutual support group are also peer-based.

There are critical points for implementing peer-based support groups, confirmed by the studies revised and the literature, and further detailed in the section on Recommendations. The most important points are to set the stage, attracting (thus, recruiting) and maintaining an active community, absorbing their ideas and evaluating the performance of the programme; these programmes, both online and offline, are context-dependent and should be carefully adapted (Amann, Zanini, and Rubinelli 2016). Peer-support, as a highly context-dependent intervention, should be properly culturally located in time, place, and target group (Dale, Williams, and Bowyer 2012). Activity and proactiveness could be raised by fostering the users' willingness for sharing ideas, the attractiveness of the program, motivations and rationale behind their engagement, interaction (then, number of peers able to interact on a regular basis) and partnership or sense of community (Amann, Zanini, and Rubinelli 2016)

Peer support is also critical for those stigmatised, isolated, socially marginalised or discriminated, as well as safe spaces, shared identities and reconstruction of the self and the sense of belonging. Mutuality and reciprocity are two key points, at least, ideally. The benefit of shared lived experience should not be undermined by the "professionalisation" of peer-support. In addition, peer-supported involvement in programmes for a very long time might lose the perspective and the strategy they themselves used in the past(Beales and Wilson 2015).

Peer supporters and supported experienced sense of connection, mutual feelings or rapport, experiential knowledge founded on living experience. Living experience is usually considered an essential resource as well as finding

and constructing meanings in chronic diseases within a safe environment – considering how these conditions often involve a sense of loss of the self, and then a loss of meaning, purpose, even hope, as well as isolation, alienation and loneliness. After the intervention, both parties - peer supporters and supported persons – may share a changed outlook, behaviour and increased knowledge about the disease and self-management skills. The empowerment – now, involving the acquisition of confidence, coping skills and sense of (individuals') autonomy – is also reported as a result of the intervention (Embuldeniya et al. 2013)

Studies analysed shown that mutual support groups would lead to "a philosophy of shared authority and group ownership" by balancing the power among members, which are findings aligned with the literature (Amann, Zanini, and Rubinelli 2016)

HCPs would find themselves "useful" for patients by providing care, in general terms, valuable information or by paying attention to psycho-emotional factors. Also, a **sense of courage** and involvement in the patients' agendas is observed. For instance, in CO17 a nurse stated "*That's my responsibility to advocate for my patient, against the doctor, against anybody for my patient*". Patients are also moved by these motivations, as has been shown above. A greater sense of credibility (EN25) could be thought of as secondary gains.

However, there the over-professionalisation of peer-support programmes should be carefully evaluated. Peer support brings wellbeing and confidence to both parts: supporter and supported; nowadays, the concept and foundations behind this approach remind unclear: there is a lack of understanding of what peer-support is and means, its assumptions and aims, leading to over-professionalisation of the process, which may threaten the transformational potential and the power balance. Peer-support is given in formal and informal settings (health education programmes or mutual support groups). Sometimes, it occurs in a spontaneous natural way, informal but intentional, for example, in the waiting room before the medical consultation (Beales and Wilson 2015). A critical barrier to consider prior the intervention is the impact on peer supporters: a review identified how the difficulty in finding peer coachers or peer mentors – who should be, in fact, a success case in a previous implementation of the programmed, changed their behaviour and/or health -, in matching supporters and supported persons, and in mitigating the psycho-emotional impact on supporters themselves are barriers (Dale, Williams, and Bowyer 2012). It has been previously introduced in the Theoretical Framework, but the intervention should also minimise the emotional impact and over-implication of supporters and empower them. Thus, peer supports may experience the value of helping or providing assistance to their peers, alleviating fears, advocacy, or confronting health disparities combating barriers and stigma, but also expecting reciprocity and mutual sharing, and a potentially excessive emotional entanglement or blurred emotional and personal boundaries (Embuldeniya et al. 2013).

In regards the health outcomes, it seems that the evidence supporting the peer-support interventions may be limited, in particular when demonstrating specific improvement in the diseases, markers and prognosis (e.g., clinical outcomes, BMI or weight, physical activity, etc.); the impact on social support, self-efficacy or improvement of mood disorders are also unclear in the case of type 2 diabetes (Dale, Williams, and Bowyer 2012)

Section 3. Adherence, compliance, self-management and decision-making

Compliance and adherence, self-management and the patients' participation in decision-making are interrelated; however, these dimensions are also linked to health literacy and to the communication during the counselling process, as the analysis of the codes and its relations demonstrated.

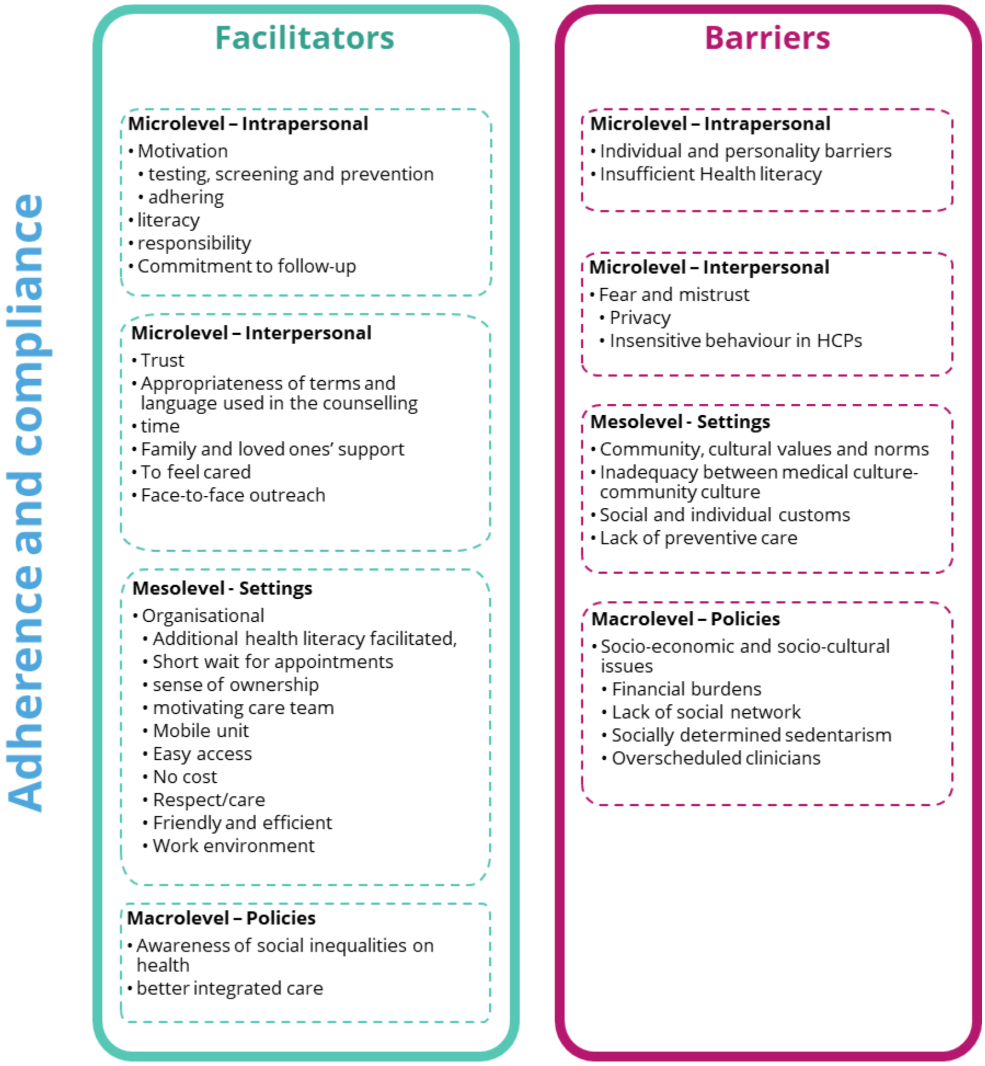
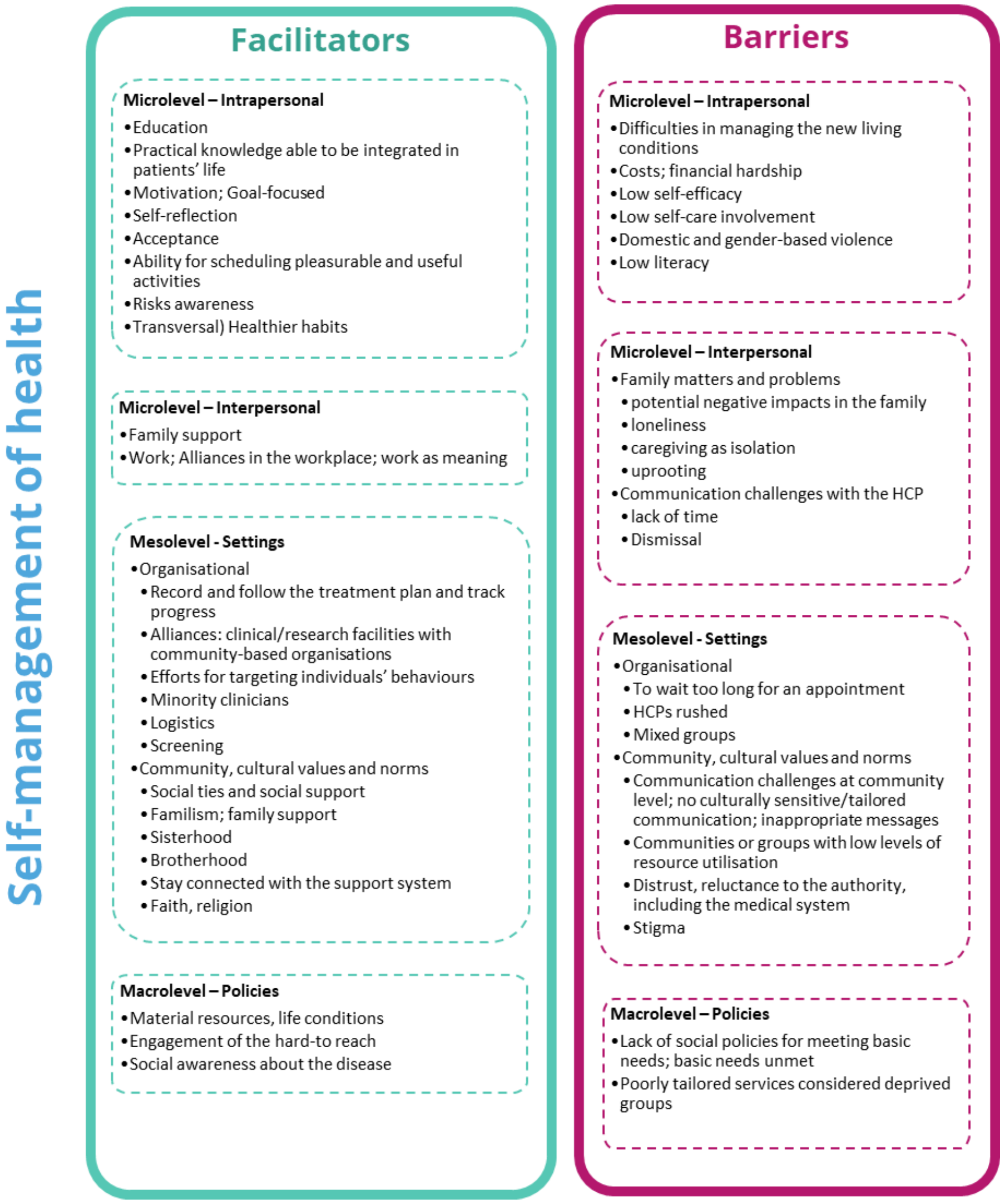


Figure 16 - Compliance and adherence barriers and facilitators

Firstly, compliance and adherence, considering that patients' proactiveness is a necessary part of this dimension, is facilitated by the patients' intrapersonal characteristics, personality and resources, such as health literacy, socio-economic issues and social environment. In this regard, the interpersonal and intrapersonal are juxtaposed, and the counselling interactions may act as a barrier or, on the contrary, as a facilitator. The organisational resources available, health literacy provided to patients, appointments wait time or location are important, as well as the interaction with the communities and the comprehension of their values, culture and norms, which mediate the individual customs and habits that, sometimes, the HCP intents to modify. Lastly, adherence is not independent of social, economic and cultural determinants, and policies should consider the financial, social and infrastructural issues that might be undermining the individuals' compliance to the medical guidelines and treatments.



Facilitators

Microlevel – Intrapersonal
- Education
- Practical knowledge able to be integrated in patients' life
- Motivation; Goal-focused
- Self-reflection
- Acceptance
- Ability for scheduling pleasurable and useful activities
- Risks awareness
- Transversal) Healthier habits

Microlevel – Interpersonal
- Family support
- Work; Alliances in the workplace; work as meaning

Mesolevel - Settings
- Organisational
  - Record and follow the treatment plan and track progress
  - Alliances: clinical/research facilities with community-based organisations
  - Efforts for targeting individuals' behaviours
  - Minority clinicians
  - Logistics
  - Screening
- Community, cultural values and norms
  - Social ties and social support
  - Familism; family support
  - Sisterhood
  - Brotherhood
  - Stay connected with the support system
  - Faith, religion

Macrolevel – Policies
- Material resources, life conditions
- Engagement of the hard-to reach
- Social awareness about the disease

Barriers

Microlevel – Intrapersonal
- Difficulties in managing the new living conditions
- Costs; financial hardship
- Low self-efficacy
- Low self-care involvement
- Domestic and gender-based violence
- Low literacy

Microlevel – Interpersonal
- Family matters and problems
  - potential negative impacts in the family
  - loneliness
  - caregiving as isolation
  - uprooting
- Communication challenges with the HCP
  - lack of time
  - Dismissal

Mesolevel - Settings
- Organisational
  - To wait too long for an appointment
  - HCPs rushed
  - Mixed groups
- Community, cultural values and norms
  - Communication challenges at community level; no culturally sensitive/tailored communication; inappropriate messages
  - Communities or groups with low levels of resource utilisation
  - Distrust, reluctance to the authority, including the medical system
  - Stigma

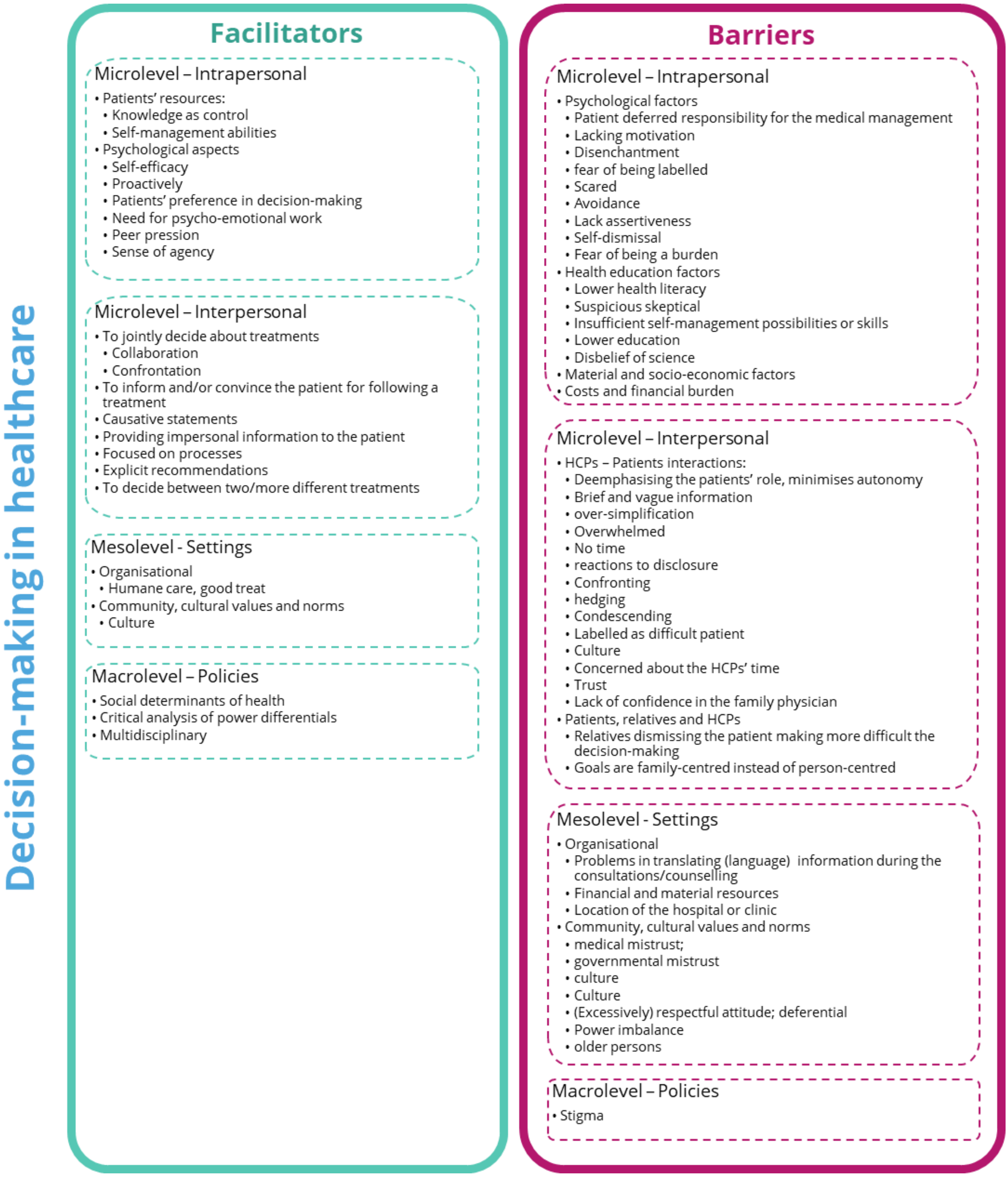
Macrolevel – Policies
- Lack of social policies for meeting basic needs; basic needs unmet
- Poorly tailored services considered deprived groups

Figure 17 - Self management: facilitators and barriers

Self-management determinants are considered at intra and interpersonal as well, also at meso and macrolevels. Again, psychological, socioeconomic and sociocultural factors are involved: motivation, the ability for self-reflection, proactive acceptance and the ability for establishing goals, objectives and scheduling effective and practical actions for reaching the aims are important facilitators for an efficient self-management, sustained by a sense of self-efficacy, appropriate self-care and a favourable social and familiar environment. Financial and economic circumstances may also be detrimental to self-management and communication challenges involved in counselling: thus, adherence and self-management showed a distinct nature for are co-determined by a similar set of factors.

At meso-level, organisational facilitators depend on the track record and its potential for motivating patients, the alliances established with key community stakeholders, efforts devoted to promote healthy behaviours, and logistics. At the community level, social ties and support, family, the sense of sisterhood/brotherhood, and feeling "connected" with the environment could be major facilitators to efficient self-management. Then, at the macro-level, again, policies should consider material resources, life conditions and put in place policies aimed at improving services for deprived communities and persons, supporting to meet basic needs and engaging the hard-to-reach by culturally-tailored care, social awareness campaigns, or other actions supported and advised by communities and civil society stakeholders.

Decision making is influenced by the patient’s resources (knowledge, self-management abilities) and psychological aspects (being the self-efficacy and proactiveness the most important ones jointly to the patients' preference for active decision-making in clinical care). The interpersonal level is determined by the counselling itself and its collaborative nature, both through cooperation and non-harsh confrontation, information provided and complete comprehension of processes, alternatives, prognosis and long-term outcomes.



Decision-making in healthcare

Facilitators

Microlevel – Intrapersonal

- Patients' resources:
  - Knowledge as control
  - Self-management abilities
- Psychological aspects
  - Self-efficacy
  - Proactively
  - Patients' preference in decision-making
  - Need for psycho-emotional work
  - Peer pression
  - Sense of agency

Microlevel – Interpersonal

- To jointly decide about treatments
  - Collaboration
  - Confrontation
- To inform and/or convince the patient for following a treatment
- Causative statements
- Providing impersonal information to the patient
- Focused on processes
- Explicit recommendations
- To decide between two/more different treatments

Mesolevel - Settings

- Organisational
  - Humane care, good treat
- Community, cultural values and norms
  - Culture

Macrolevel – Policies

- Social determinants of health
- Critical analysis of power differentials
- Multidisciplinary

Barriers

Microlevel – Intrapersonal

- Psychological factors
  - Patient deferred responsibility for the medical management
  - Lacking motivation
  - Disenchantment
  - fear of being labelled
  - Scared
  - Avoidance
  - Lack assertiveness
  - Self-dismissal
  - Fear of being a burden
- Health education factors
  - Lower health literacy
  - Suspicious skeptical
  - Insufficient self-management possibilities or skills
  - Lower education
  - Disbelief of science
- Material and socio-economic factors
- Costs and financial burden

Microlevel – Interpersonal

- HCPs – Patients interactions:
  - Deemphasising the patients' role, minimises autonomy
  - Brief and vague information
  - over-simplification
  - Overwhelmed
  - No time
  - reactions to disclosure
  - Confronting
  - hedging
  - Condescending
  - Labelled as difficult patient
  - Culture
  - Concerned about the HCPs' time
  - Trust
  - Lack of confidence in the family physician
- Patients, relatives and HCPs
  - Relatives dismissing the patient making more difficult the decision-making
  - Goals are family-centred instead of person-centred

Mesolevel - Settings

- Organisational
  - Problems in translating (language) information during the consultations/counselling
  - Financial and material resources
  - Location of the hospital or clinic
- Community, cultural values and norms
  - medical mistrust;
  - governmental mistrust
  - culture
  - Culture
  - (Excessively) respectful attitude; deferential
  - Power imbalance
  - older persons

Macrolevel – Policies

- Stigma

Figure 18 - Decision-making: facilitators and barriers

At the organisational level, the humanisation of treatment and person-centred care at the clinic level seem to be the most determinant facilitators for promoting a proactive decision-making process. However, culture and social environment may suppose a significant barrier for severely marginalised and/or discriminated communities and persons. At the macro-level, policies should actively promote an active role for patients, but also tackling the social determinants for proposing public health interventions and regulations, facilitating a multidisciplinary approach to the most vulnerable patients and a critical analysis of power differentials and social, economic and cultural issues involved in healthcare and within the institutions.

Critical factors in adherence and compliance

Compliance and adherence mean the patients' willingness and abilities to accomplish the treatment instructions or follow the HCPs' guidelines; while **compliance** involves a more passive component, the **adherence** seems to require the patient's proactiveness (Lutfey and Wishner 1999). Both are jointly discussed in light of their micro, meso and macrolevel determinants.

Throughout the studies, **responsibility and avoidance** play an essential role in adherence and compliance. On the one hand, **responsibility** appeared as the most important factor (linked to the commitment to follow up. The literature reflects the responsibility as a personality factor as a mediator in self-management expectancies by the patient – and by the provider – and a determinant for the patients' preparation for facing complex chronic diseases self-care, increasing their sense of control and self-efficacy and opening paths for a more effective self-management (Lawn, McMillan, and Pulvirenti 2011; Redman 2007; Curtin et al. 2008; Bradley 2013, chap. 15).

On the other hand, **avoidance** may involve not attending the medical visits or minimising the condition and hindering information to the practitioner. Avoidant or socially inhibited behaviours sometimes led to perceive the **self-care as a burden**; the role of avoidant and socially inhibited behaviours in self-management, even in adherence, is well demonstrated; literature showed a lack of sufficient information exchange in the medical consultation, insufficient disclose of patients' key problems and issues and increases distress related to the diagnosis (Schiffer et al. 2007; Pelle et al. 2010; Iturralde, Weissberg-Benchell, and Hood 2017).

Other psych emotional factors that play a role are fear, motivation or powerlessness. Firstly, **fear** may be a facilitator of adherence, but fear might also be a barrier leading to a sense of **powerlessness**[16]. In regards to motivation, the

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[16] This contrast is observable in (CO23)(EM06)(EN14)(EN34) versus (CO20) (EM17) (EN01) (EN17) (EN38); it may be hypothesised that the difference relies on the intrinsic nature of the fear versus the fear by being (extrinsically) frighten.

intrinsecal desire to preserve or improve **wellbeing** is one of the most mentioned facilitators, jointly with the proactive **acceptance** of the disease.

At the intrapersonal micro-level, studies revised confirmed that **motivation** plays a major role in adherence; motivation also increases the participation in testing, screening or prevention campaigns, being the motivation to make more informed decisions. Lastly, individuals' motivation is, at the same time, mediated by individual personality traits: for instance, personality traits are related to the adherence to exercise and healthier eating patterns, as well as to increase the patients' sense of helplessness (Mackey et al. 2016).

Given the importance of the psychological and personality factors in adherence and compliance, it is comprehensible and meaningful the importance that providers-patients **trust** has in the revised studies and how mistrust led to fear [17]

Besides, individuals' **health literacy** plays a critical role[18]. In line with the literature, poor health literacy may lead to health misunderstanding and false beliefs: for instance, patients might misunderstand the sense of the recommendations, the information received, or abandon the treatment. Literature suggests that health literacy and, in general, education and qualification impact self-care and self-management, including adherence (Mackey et al. 2016). A vast body of research has shown how better-educated patients show better health outcomes (J. M. O'Mahony and Donnelly 2013; Tillmann et al. 2017), but these factors are systemic and out of the control of the individual, mediated by the transgenerational reproduction of education and social class (Bourdieu and Passeron 2008; Foucault 2009; Planas Coll and Casal Bataller 2003; Stinchcombe 1972).

At meso level and linked with the previous mention to social support, the **community and its values** and norms may be in "conflict" with the recommendations: in other words, the treatment may be non-culturally tailored (Yilmaz et al. 2017), which involves a problematic inadequacy between medical culture and the **community culture** entering in conflict with social and groups' customs, thus **hindering the adherence**; concerning these culturally-rooted customs, the social nature of food is a pivotal issue to be considered. In fact, some groups are

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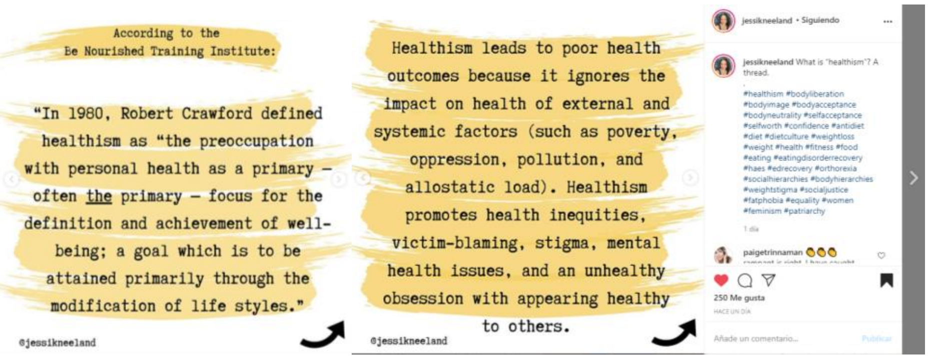
[17] Some examples are (CO06) (CO23) (ED9) (EM04) (EM07) (EM08) (EM16) (EM17) (EN01) (EN02) (EN09) (EN36) (EN42).

[18] This is a frequently occurring relationship; for instance, appearing in (CO09) (CO23) (CO26) (EM07) (EM08) (EM17) (EN05) (EN18) (EN35) (ED9)

distrustfully **confronted with medical**. A sense of joint ownership, culturally-tailored care and respect for their traditions are lacking.



According to the
Be Nourished Training Institute:

"In 1980, Robert Crawford defined healthism as "the preoccupation with personal health as a primary – often the primary – focus for the definition and achievement of well-being; a goal which is to be attained primarily through the modification of life styles."

@jessikneeland

Healthism leads to poor health outcomes because it ignores the impact on health of external and systemic factors (such as poverty, oppression, pollution, and allostatic load). Healthism promotes health inequities, victim-blaming, stigma, mental health issues, and an unhealthy obsession with appearing healthy to others.

@jessikneeland

jessikneeland • Siguiendo

jessikneeland What is "healthism"? A thread.
.
#healthism #bodyliberation #bodyimage #bodyacceptance #bodyneutrality #selfacceptance #selfworth #confidence #antidiet #diet #dietculture #weightloss #weight #health #fitness #food #eating #eatingdisorderrecovery #haes #edrecovery #orthorexia #socialhierarchies #bodyhierarchies #weightstigma #socialjustice #fatphobia #equality #women #feminism #patriarchy

1 día

paigetrinnaman 👏👏👏

250 Me gusta

HACE UN DÍA

Añade un comentario...

Publicar

Screenshot 1 - Healthism and the social determinants of health (pictures 2 and 6)
Source: https://www.instagram.com/p/CF-ieP-ljLu; 7.10.2020

The organisational settings are also relevant. Additional **health literacy** in **peer-based** or any other form of health education programmes, easily and low-cost/freely available, can enhance their **proactive adherence** (see the previous section for more insight about health education). Other factors are: **short wait** for appointments (EN02) (EN09) and a **motivating** care team. Inline, the **lack of preventive care** supposes a problem: these factors are inter-related to macro-level issues concerning healthcare policies and the healthcare system's organisation.

At the macro-level, **the impact of social determinants of health and health inequalities** should be cleared, and how these impact the engagement, health outcomes, possibilities to adhere and issues that may arise (Dalgard, Bjørgulf Claussen, and Michael McCubbin 2009; Graham, Kelly, and NHS Health Development Agency 2004; Trinh-Shevrin, Islam, and Kwon 2015). Some of them appearing during the research on the adherence-related field are **financial burdens, lack of social support, socially determined sedentarism by the unavailability of sport and physical exercise facilities in rural, isolated and/or deprived areas, gender, sexuality and ethnical-related determinants.**

dietitiananna Health is not an equal opportunity experience.

It is impacted by a multitude of factors. That are largely outside of most humans control. This is not about not working hard enough. This is not about modifying priorities. This is not about pulling oneself up by their bootstraps. This is not about love and light and best wishes.

Health is not simply about what someone eats or doesn't eat. Or simply about how someone moves or doesn't move. Or how committed someone is to engaging in 'health promotion practices.'

Les gusta a oona_hanson y 1.975 personas más

30 DE JUNIO

Screenshot 2 - Health inequalities and bio-psycho-social determinants. Source: https://www.instagram.com/p/CCDtEUEpSSB/, 7.10.2020

Self-management determinants

As previously introduced, in regards to intrapersonal micro-level factors, self-management is related to **health-literacy** and the ability for knowing and **understanding** medical information; thus, **make sense of the instructions and recommendations**[19]**. Previous education** is an essential factor, a facilitator, and, at the same time, a social determinant that is, to some extent, out of the control of the individual.

A major barrier for an effective self-management, now modifiable, are the difficulties in **integrating the disease in the individuals' lives**[20] **and a low self-efficacy**: the **obligations** may be seen as unfeasible, the **required changes** might be challenging for the person or the **support** received by HCPs may be lacking; above all, individuals might need to develop new and complex coping skills, some of them require appropriate social support and a favourable environment. Literature shows how emotional support is a priority for patients facing coping diseases, above

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[19] This is a very important point; in fact, appears repeteadly in the studies, for instance in (CO01) (CO08) (CO19) (CO31) (CO38) (ED2) (ED5) (ED6) (ED8) (ED13)) (ED15) (ED16)(ED6) (EN01) (EN14) (EN29) (EN34) (EN37) (EN38) (EN39) (EN45) (EM09) (EM12) (EM13).

[20] Difficulties for integrating the chronic disease in individuals' life are a very important and tough barrier, appearing in several studies; e.g., (CO04) (CO08) (CO15) (CO31) (CO36) (EN01) (EN14) (EN37) (ED10) (EM04) (EM07) (EM08) (EM12) (EM13) (EM16) (EM17) (EN05) (EN23) (EN24) (EN34) (EN35)

information or instrumental support, close relationships, and a favourable social environment enhanced motivation and provide important coping strategies. Coping with chronic illnesses is mediated by social support, personality, patients' perceptions about the illness and demographic variables (Milette et al. 2020; Petrie and Jones 2019).

Considering the coping strategies, again, and as previously considered for adherence, **personality fa**ctors are related to self-manage a disease; specifically, **responsibility** appears again, and **goal-focused** attitudes are linked to a sense of **ownership** and **accountability** also a **sense of purpose** and **advocacy**. Also, the abilities and **willingness to structure their lives and get organised** are relevant and related to greater **self-efficacy** and most successful **self-care** able to **integrate practical knowledge** in quotidian routines.

Contextual factors play a role in the availability and readiness for sticking to healthier behaviours (e.g., financial hardships, problems of accessibility, etc.). Contextual factors mediate in the possibilities to implement, autonomously, a physical exercise routine or acquiring healthier dietary patterns[21].

The interpersonal micro-level dimension highlights the **role of the relatives and loved-ones as support and** the role of **peers**, **civil society organisations** (e.g., associations) or individual **counselling** with HCPs as facilitators for effective self-management, increasing the access to crucial knowledge and autonomy.

In general terms, self-management is viewed by providers, even by patients, as compliance, more than decision-making. Decision-making is linked to health literacy and credentialism also from the point of view of patients[22]

To address the minorities in a comprehensive and **culturally appropriate** way and **reduce social disparities and systemic inequalities severely impacting** life conditions is critical if promoting effective self-management for more vulnerable individuals and communities is a goal (Browne et al. 2012). Lastly, self-management is easier if the whole society does not stigmatise the disease: more **social**

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[21] It will include to re-adopt the CALD's traditional diets (Lindeberg 2010; Lipski 2010; Truesdell et al. 2018)

[22] For instance, HCPs might restrict who could and who couldn't implement a self-management routine based on the age (EN23) and class (i.e., CO38, applied to migrant status, social, economic and cultural status and positions), also limiting the self-management capabilities of frail patients (EN23) or newly diagnosed (EN33). In fact, HCPs desire that patients fully align with their expectations and goals (CO19) (CO27) (EN23) (EN24) (EN29) (EN37) including the compliance (CO19) (CO31) (EN23) (EN24) and the acceptance of the severity as perceived by the provider (CO19) (EN29) (EN37) (EN42)

awareness campaigns about stigmatised diseases are needed. **Stigma, self-stigma** and **communities' distrust of authorities** are relevant as long as these suppose a barrier for accessing care, appearing in the studies and frequently discussed in the literature (Chenard 2007; Kato et al. 2016; Schabert et al. 2013).

Decision-making and health decisions

Decision-making depends on a vast complex range of factors; at individuals' level, it depends on patients' resources and psychological aspects: **the knowledge, which provides a sense of control**, depends on **previous education**, to which extent their **informational needs are being met** in the consultation – while persons with lower education seem to be more satisfied with no joint decision-making - and the **ability for self-directing their own health literacy** as well as the higher socio-economic position.

It should be noticed that, while the relation between previous education/credentials and health outcomes appears again (this time, due to the better ability for making decisions), to meet the patients' informational needs – **the acquisition of knowledge through the relational dimension - seems to be more important than the patients' resources.** Apart from knowledge, the **self-management abilities acquired are an essential resource for decision-making** –also considering that self-management possibility are socially mediated too (e.g., availability of sports facilities, groceries and food insecurity, among other disadvantages at material and environmental level). Likewise, it is relevant how these circumstances and possibilities are aligned with the **treatment goals**.

The link between health literacy and decision-making is clearly demonstrated by the research, as well as the studies revised in the present dissertation**: precisely the link between these dimensions is the key point for establishing a relation between health literacy and the responsibility as a dimension of one's autonomy**: health literacy covers the knowledge of health but also the healthcare system, the ability for processing and using the information and the applied competency for self-managing health and be proactive in decision-making (Liu et al. 2020).

Regarding the barriers, joint decision-making might be challenged by suspicious or **sceptical** attitudes. Another barrier is that patients **may defer healthcare and medical management responsibility** or may have a **lack of desire for information**. The sense of **powerlessness**, **self-dismissal** or **avoidance** can impede or determine an underwhelming environment for decision-making in healthcare. Also, patients might be **disenchanted** with the healthcare system or be **afraid of being labelled** or **stigmatised**; literature also addresse**s this issue** (Kato et al. 2016; Chenard 2007). Interestingly, **trust** in the HCP can be a barrier to joint decision-making, tending to over-delegate in the provider[23].

Material circumstances should also be considered (e.g., lower education, financial burdens, or healthcare costs).

Internal (intrapersonal dimension) factors are mediated by the sense of autonomy, self-efficacy and proactiveness; **self-efficacy** and **proactiveness** are the major facilitators, as long as them are needed for fostering the **desire** for engaging in decision-making. The autonomy is crossed with the proactiveness and expressed through **setting priorities**, sustaining a sense of accountability and **responsibility** for their own care which led to a more proactive approach to decision-making, including to look for **second opinions** when required, **engaging with peers and survivors**, choosing more **trustable HCPs**, **negotiating**, even **postponing** treatments. Literature shows that intrinsecal facilitators of patients for being engaged in health care are empowerment, self-caring skills, copying strategies health status, flexibility and confidence in oneself (Frost, 2015)

At the interpersonal level, the **joint decision about treatments** can be approached from the collaboration or the **confrontation**, being both vehicles to promote proactiveness. On the contrary, HCPs **minimising patients' autonomy may challenge the decision-making, for instance, by disregarding the experiential knowledge or providing excessively brief information, vague explanations,** or oversimplifications. On the contrary, to provide too much overwhelming information, using harsh confrontational communications styles, as previously discussed, is discouraging, impacting negatively in self-management and self-care - and are, also, a barrier for decision-making for promoting patients' autonomy. Self-efficacy, mutual respect, understanding, readily available, reliable, timely information, reinforced by education, goal setting and listening time are also characterised as crucial factors in the literature (Frost, 2015) as well as a sense of power balance and power-sharing in the medical consultation (Edwards, Davies, and Edwards 2009)

In relation, contexts are settings are crucial and should be considered for all patients but, most important, for vulnerable and at risk of social exclusion groups,

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[23] Trust appears linked to defer the responsibility for healthcare in HCPs (CO11)(CO14) (ED14)(EM11).

communities and persons: **culture and cultural values** may impact on the patients' ability or willingness to **discuss, collaborate and confront**; the **organisational cultures** are also central as well as the importance is given within an organisation to the humanisation of care, and how it impacts, at inter-personal level, in the rapport and the therapeutic relationship. Some groups and communities might show a **profound distrust in authorities** (and among them, HCPs) because of mistrusting the government, **previous negative experiences** with law or authorities or by having suffered **historical atrocities;** also, an excessively **deferential a**ttitude in front of authority figures (or generational factors may undermine the decision-making in patients due to cultural reasons.

Lastly, at macro-level, the critical analysis of the health inequalities and the social determinants of health remains crucial and **multidisciplinary** in the healthcare models. To give voice and choice to communities and groups in overcoming the stigma and discrimination are required steps in the field of policies for raising the capacities of decision-making and improving the populations' health outcomes.

Findings on factors determining the patients' decision-making skills are consistent with the literature. Social Determinants of Health also determine and shape knowledge, behaviours, access to health care, and are related to beliefs, abilities, and health conceptions and assumptions.

Research on health failure and social determinants of health impacting on decision making (Enard and Hauptman 2019) shown that the decision-making process is influenced by **economic status** (financial uncertainty, burden or constraints can increase the conflict in decisional settings and reduce treatment adherence), **education** (fewer education, low socio-cultural status, low health literacy and numeracy and reduced abilities and competencies for accessing to information affect to risk perception and assessment, self-efficacy, HCP-patient communication and proactiveness in the counselling), **social and community settings** (language barriers, cultural norms or stereotypes undermines the HCP-patient communication as well, being a potential hazard for joint decision-making), **health and healthcare access** (insurance coverage, difficulties for paying for specific treatments, or co-pays impact on treatment choice, adherence and may generate decisional conflict) and the **neighbourhood, built environment and infrastructures** (hazardous environments, unsafe housing or neighbourhoods, poor access to fresh healthy food, poor access to sport facilities offer poor support for adherence and impede value clarification, increasing the decisional conflict and regret in decision-making processes). In situations non-directly related to chronic disease self-management and decision-making, co-determinants appearing are **education** and **occupation**, reflecting independence, control, and social network (Kiani et al. 2016). Race and ethnicity are an important social determinant of health and access to healthcare due to the **structural racism**; structural racism impacts on providers' biases on joint decision-making and in the treatments' prescription; for instance, paediatricians showed more **implicit biases** prescribing narcotic medications for postsurgical pain for white children than for black children, or, in adults, HCPs show higher verbal dominance and reduced patient-centred measures, trust and interpersonal care, concern and respect with black patients. Thus, "there is sufficient evidence to suggest that eliminating health care disparities requires providers to identify and mitigate the effects of their own implicit bias on patients and families" (Johnson 2013)

Section 4. Empowerment and empowered communities

Autonomy and collective empowerment are intrinsically linked and related to health literacy, decision-making and proactiveness and self-management skills, and social, cultural, economic and environmental determinants underlying the whole complex set of factors at macro and structural level.

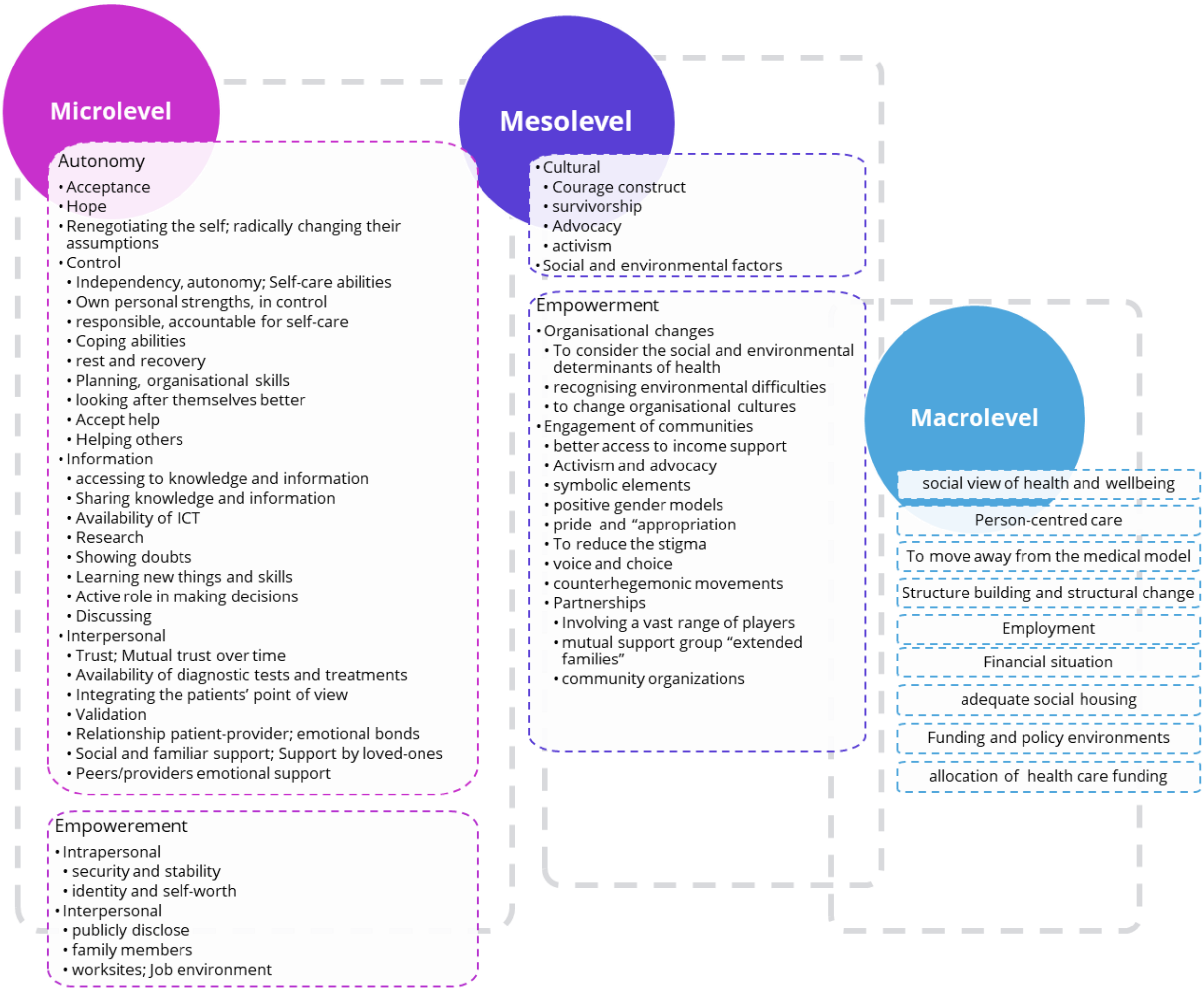


Figure 19 - Factors involved in community empowerment

Empowerment at the collective level is enabled and determined by the individuals' empowerment and autonomy, and vice versa: in other words, autonomy and empowerment, individuals and communities, interacts and learn mutually over time. Collective empowerment is needed for building autonomy; the autonomy, sense of control, the capacity for helping others, the access to essential and basic services and needs (healthcare, education, housing, etc.) and the ability to trust others - including HCPs - is required for fostering the communities' empowerment. At the intrapersonal level, communities' empowerment requires that community members feel security and stability and have to build a sense of identity and self-worth, overcoming powerlessness and disempowerment. The involvement of the immediate social networks and the acknowledgement and validation of the individuals' lived experiences are also critical at the interpersonal level for building sustainable and robust structures that can support an empowered community.

The sense of autonomy is culturally and socially determined. Some constructs such as 'courage' and 'survivorship' are relevant and can be crystallised into advocacy and activism: both, activism and advocacy can directly foster the empowerment of communities and collectivities. The empowerment, here, is determined by the organisational changes in healthcare, education or social services: the acknowledgement and consideration of the social determinants and the change in organisational cultures are relevant. The engagement of communities precedes their empowerment through gaining better access to income support, symbolic elements (e.g., symbols and international days, memorials, cultural expressions, protests, etc.), positive role models (including gender models), price and "appropriation" (including the appropriation of insults when extreme discrimination is present, eg., ‘nigger’, ‘queer’, ‘fag’, ‘fat’, , ‘slut’, ‘mad’, etc.) and the raise of counterhegemonic movements for providing voice and choice to oppressed communities.

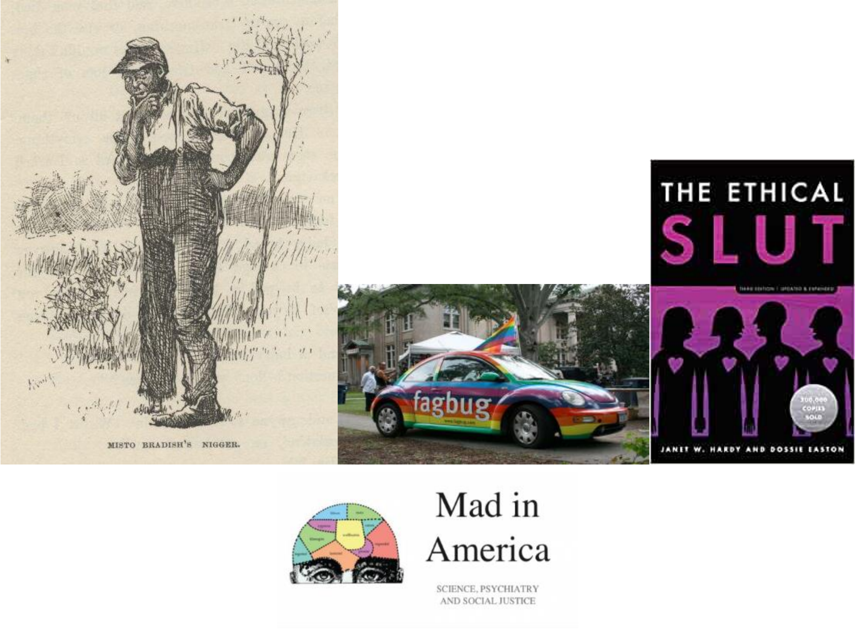


Illustration 1 - Examples of symbolic (re)appropiation

Then, partnerships with institutions - including healthcare, research, education or social agencies - should involve a vast range of stakeholders and should also, give enough voice to community stakeholders, with a particular emphasis on leaders.

At the macro-level, a socially informed view of health and wellbeing, person-centred care, overcoming the 'medical model' to promote the structural change, and addressing the most urgent problems (employment, financial hardships, social housing, funding, and policies). Socially informed perspective is critical for building long-term structures facilitating the empowerment of communities.

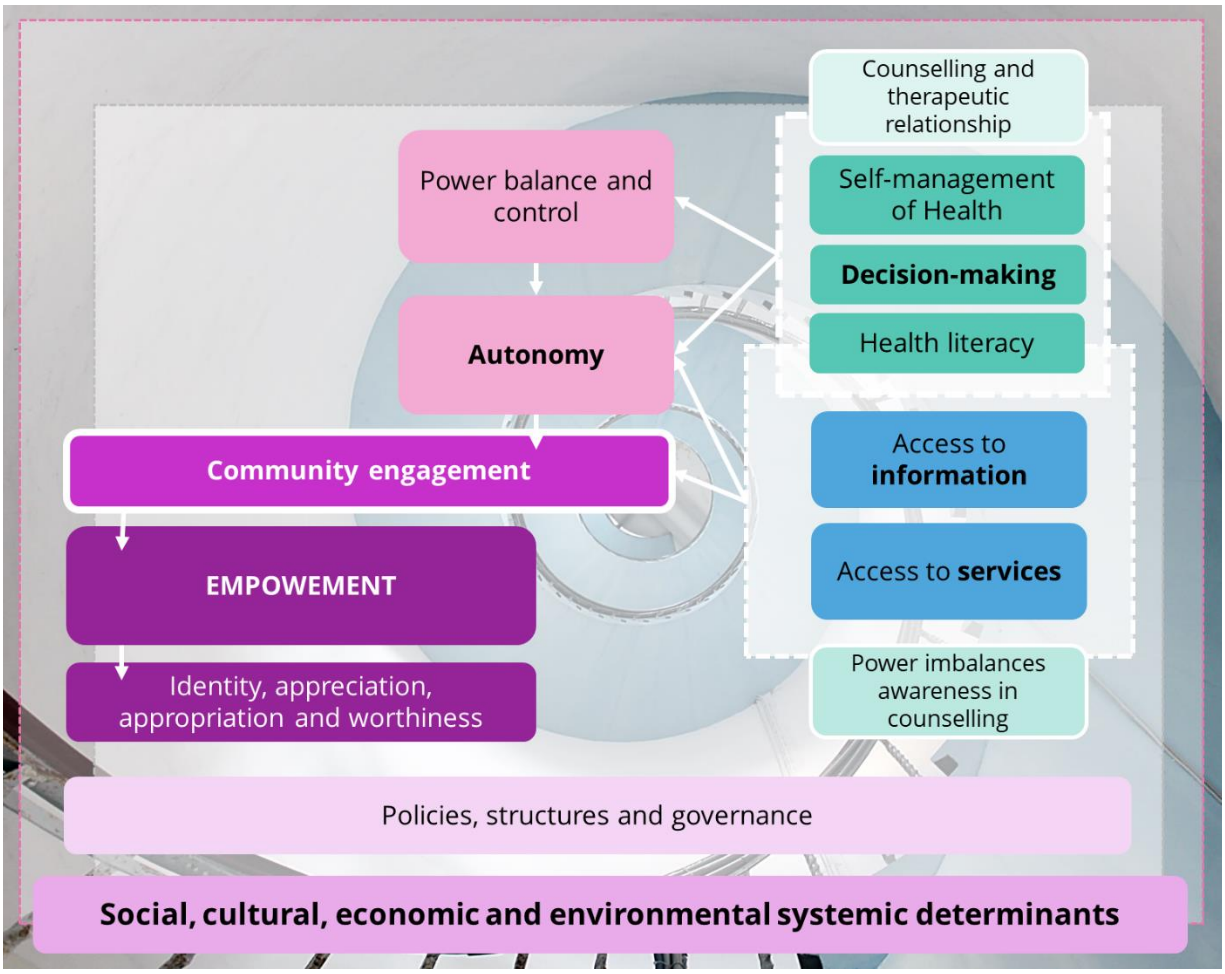


Figure 20 -Processes and co-determinants involved in patients' autonomy and communities' empowerment in health

This section discusses the results and the evidence gathered from the literature. It is divided into the individual and collective levels of empowerment; thus, the sense of autonomy at a personal subjective level and the empowerment at a community level. **Empowerment** is understood in this dissertation considering three key elements: (iii) locus of control; (ii) advocacy; and (iii) counter-hegemonic rupture. Usually, *empowerment* could have a more **individualistic** meaning, involving both autonomy and control and 'informed patient' or 'reflexive consumer' (Edwards, Davies, and Edwards 2009). At **community** level, empowerment as **advocacy** aims to raise the capacity of individuals and communities to control their circumstances by exercising power framed in collective and collaborative efforts. In order words, and specifically applied to health promotion, it implies "identity, knowledge and understanding, personal control, personal decision-making, and enabling other patients" (Small et al. 2013). Finally, at **social** level, empowerment sometimes involves a **rupture** of the hegemonic order – or the status quo – in which counter-hegemonic forces/groups dispute their own rights and, thus, power in conflict with the ruling elite/s. This notion related to the rights and collective identity of discriminated minorities (eg., ethnic minorities) implies deeper and substantial changes in the societal and systemic order itself (Griffin 2017; O'Campo and Dunn 2012).

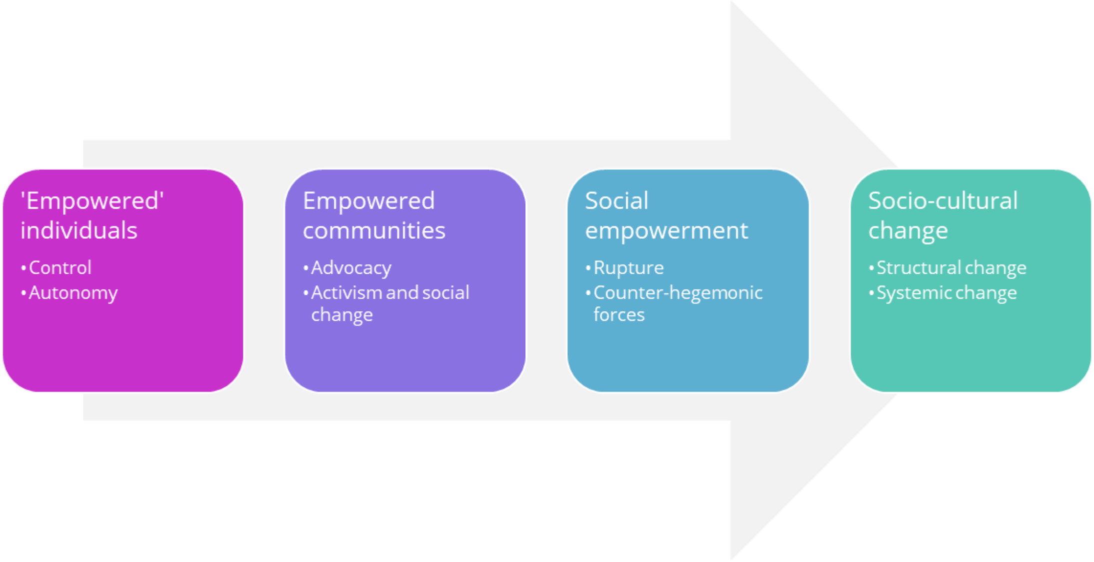


Figure 21 - Empowerment process

Empowered communities and social change

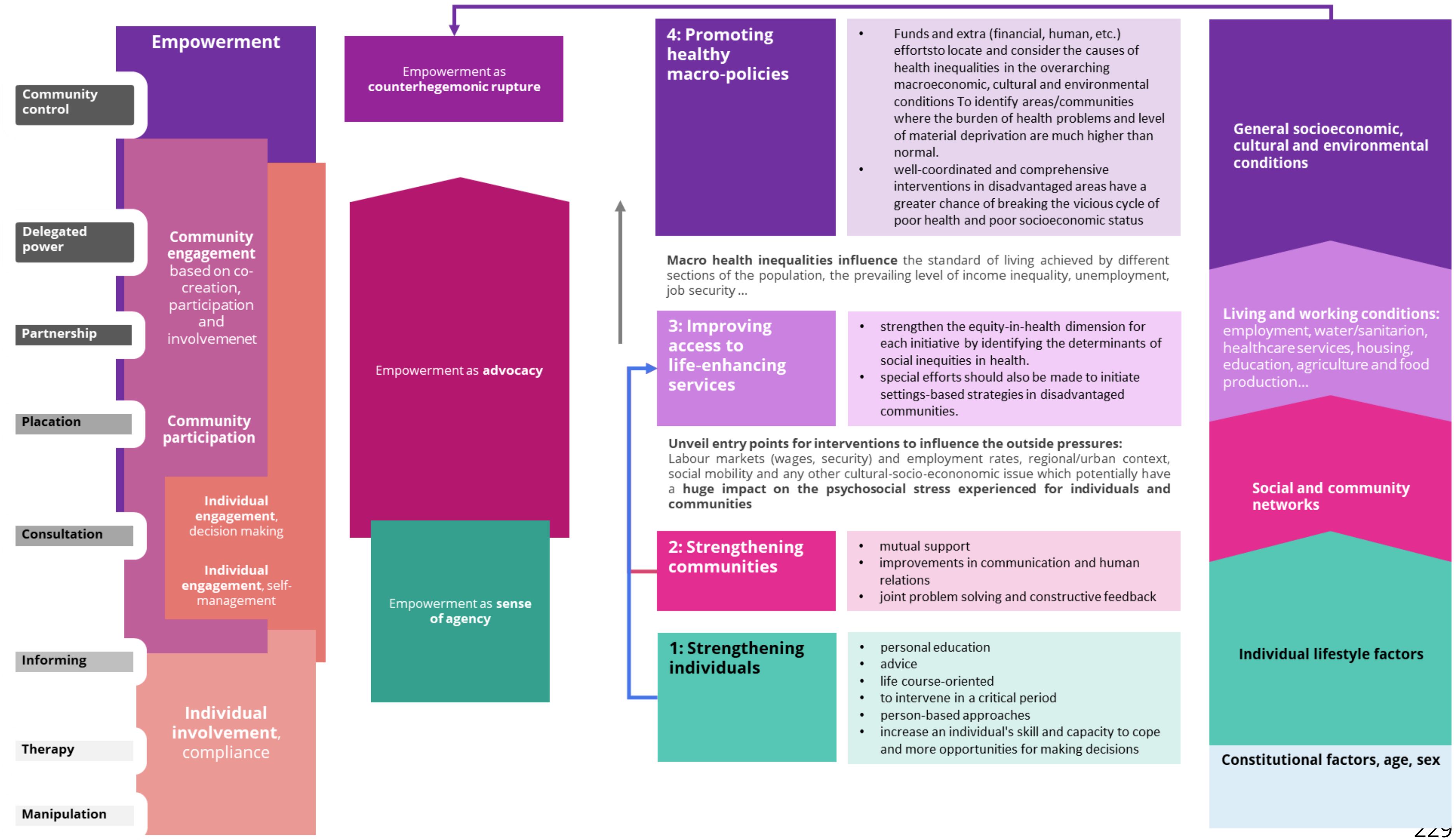
The role of organisations – including healthcare or research institutions – is critical in facilitating or making particularly difficult the empowerment of communities; those actors undertake the positions – by definitions, they are viewed as outsiders by themselves and the community stakeholders. In particular, health and social care organisations should consider the social and environmental determinants of health to overcome prejudices, stigma or to reproduce the health inequalities that are supposing the major vulnerability factors of those populations. Health and wellbeing should be framed within a broader social perspective, and basic necessities cannot be ignored when proposing solutions or strategies for community and public health. Thus, social housing, funding and policies at a regional or local level, access to income support or benefits, to recognise the environmental difficulties and to move away from the traditional 'medical model' are critical steps in supporting the communities' process for building structures and changing their current conditions. Health and social care organisations, then, could co-produce person-centred care, focused on the real necessities and priorities.

It should be taken into account, also, that communities may face real difficulties and barriers for implementing or "adhering" to public health recommendations. Mainly, the most important difficulty is the lack of resources, in general, and, in particular, the problems in accessing healthcare, insurance issues and healthcare fees, the job insecurity, housing insecurity, neighbourhood issues at the infrastructures level and a lack of self-care necessities, such as vacation time. For instance, neighbourhoods without appropriate parks, pavements and sidewalks will suppose a barrier for adhering to physical activity recommendations; precarious and intensive jobs, and mini-jobs, also suppose a lack of leisure and vacation time. Thus, it implies difficulty adhering, again, to physical activity prescriptive advice in public health campaigns.

This conflict between the community's reality and the 'lifestyle' guidelines prepared and disseminated in public health campaigns can result in an alienating and disempowering process; ultimately, it could disengage the community to the health issues or health 'authorities'. The **community-centric approach** emerges as a necessity, as the integrative process which is able to overcome the traditional biomedical model's limitations - such as the immutability of individual risk factors or the restrictive focus – by considering the bio-psycho-social perspective (O'Campo and Dunn 2012). Community-centric approaches can unveil factors that may condition the acceptance of public health campaigns or behavioural change. Consequently, engagement and empowerment are central concepts.

Figure 22 - The relation between ladders of participation, typology of intervention and research, social determinants of health, engagement, and empowerment.

Prepared by the authors based on the literature (Dahlgren and Whitehead 2007; Whitehead 2007; Arnstein 1969)



4: Promoting healthy macro-policies

- Funds and extra (financial, human, etc.) effortsto locate and consider the causes of health inequalities in the overarching macroeconomic, cultural and environmental conditions To identify areas/communities where the burden of health problems and level of material deprivation are much higher than normal.
- well-coordinated and comprehensive interventions in disadvantaged areas have a greater chance of breaking the vicious cycle of poor health and poor socioeconomic status

Macro health inequalities influence the standard of living achieved by different sections of the population, the prevailing level of income inequality, unemployment, job security ...

3: Improving access to life-enhancing services

- strengthen the equity-in-health dimension for each initiative by identifying the determinants of social inequities in health.
- special efforts should also be made to initiate settings-based strategies in disadvantaged communities.

Unveil entry points for interventions to influence the outside pressures: Labour markets (wages, security) and employment rates, regional/urban context, social mobility and any other cultural-socio-econonomic issue which potentially have a **huge impact on the psychosocial stress experienced for individuals and communities**

2: Strengthening communities

- mutual support
- improvements in communication and human relations
- joint problem solving and constructive feedback

1: Strengthening individuals

- personal education
- advice
- life course-oriented
- to intervene in a critical period
- person-based approaches
- increase an individual's skill and capacity to cope and more opportunities for making decisions

Communities' norms and values should be considered, again, in order to overcome the power imbalance but also for offering recommendations and guidelines that make sense and can be implemented in real-world settings. It implies considering, as a whole, the cultures and the cultural background of all communities targeted and consider how the power imbalance is reproduced in the medical, research or social-care discourse to impairment-based approaches, intimidating styles and campaigns, lack of intercultural discourse of illnesses and disorders, overt discrimination, alienating styles of communities and practitioners' biases that only can be superseded by their introspection and openness– thus their ability for examining their preconceptions, self-reflection about their own cultural background and pre-conceived notions about communities, practising cultural humility (Shea et al. 2017)**.** Researchers must be willing to share knowledge with the community, to learn about the community and the stakeholders involved, mapping representativeness, leaders, relationships, historical events, power dynamics or customs, to perform a realistic needs assessment focused on them and their priorities (Gagnon et al. 2014; Nueces et al. 2012; George et al. 2015; Shippee et al. 2015). **The practitioners' attitude towards the community empowerment should be open-minded and sincere, founded on a listening non-paternalistic attitude**. Healthcare entities and researchers still sustain non-participative traditional approaches, and the process of participation is understood as a process of delivering information and then, consultation(Gagnon et al. 2014) rather than establishing a more profound relationship and engaging in co-production processes.

However, communities and patients' groups can also experience some internal barriers, again related to disengagement; weaknesses of the advocate organisations, and the polarisation and atomisation of organisations or communities. Individual practitioners may experience difficulties in power-sharing and collaborative decision-making; they may feel powerless and not completely understand how collaborative practices are planned and executed. Tokenism may be also present, supposing a significant barrier for community empowerment.

On the contrary, activism and advocacy reinforce and facilitate empowerment and led to obtaining more significant information and health literacy, fostering the community's identity, self-worthiness, price and reappropriation of symbols and cosmovision. All these necessities and requirements will need to establish long-term and sustainable partnerships with organisations and communities by involving a vast range of stakeholders, promoting the socialisation and bonding between the community members or patients[24], acknowledging the mutual support groups and peer-supported interventions as legit parts of the process with their own entity and intrinsically value and engaging community organisations, leaderships and, when applicable, patients' advocates to **prioritise the communities' specific, idiosyncratic and particular problems**.

The partnership with the communities should be designed and prepared for a collaborative effort, facilitating dialogue, coordination and decision-making. To integrate the formal and informal processes in the community for decision-making, collaboratively outlining the priorities and obtaining the commitment of organisations and leaders for the co-production process is crucial. Communities must also be involved in the design phase possible (Gagnon et al. 2014; Forsythe et al. 2014). It is worth highlighting that data collection, interpretation and exchange and co-ownership of data are very complex issues that could be discussed in terms of the consequences of these processes for the groups themselves. Data gathering may be detrimental to deprived or marginalised communities. Besides, the indicators may be culturally inadequate, the stakeholders may be under-represented or disregarded, and the results are, sometimes, inaccessible for them (O'Campo and Dunn 2012; Small et al. 2013). The equitable distribution of resources and credit, including financial resources, resource distribution, media coverage and scientific publications, is also a necessary step beyond the traditional models (Shea et al. 2017).

'Empowered individuals': the relation between patients' autonomy, advocacy and power balance in decision-making.

The **living experience** during the disease is impacted and impacts the sense of autonomy of individuals. Sense of autonomy refers to the individuals' control over their actions, consequences, and decisions (J. W. Moore 2016).

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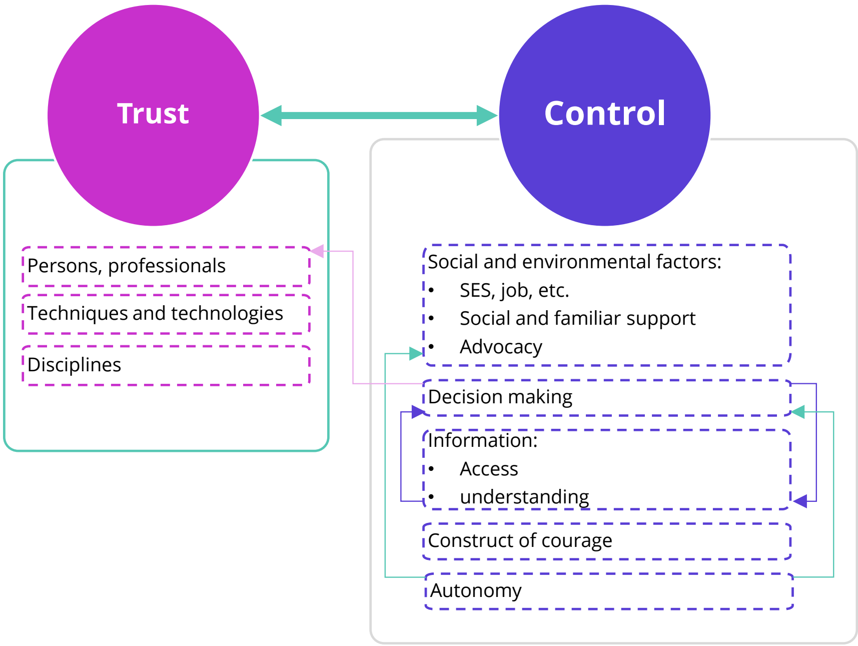
[24] Some valuable and illustrative examples can be found in (CO26) (ED8) (EM09) (EM10) (EM13) (EM15) (EM19)(EN01) (EN20)

Figure 23 - Trust and control



Results showed a complex iteration between trust and control as the main determinant of the sense of autonomy as summarised in Figure 22. These dimensions are inter-related and linked to the previous themes, which are decision-making, health literacy and counselling communication, but also to other socio-cultural constructs and determinants. **Trust** appears linked to other persons, such as peers and HCPs, but also techniques or disciplines (e.g., the specialist vs the general practitioner). The **control** appears linked to decision-making and information available - then, vinculated to trust in HCPs as well - but also the construct of 'courage' and the ideas and perceptions around the 'autonomy' appeared.

Firstly, the trust may refer to persons or techniques. Concerning persons and, in particular HCPs, the trust is developed over-time; also, in peers/group settings, time is required. It is also essential to select a subjectively trustable professional. Secondarily, the trust in techniques or technologies depends on its availability and the preventive actions, such as screening, could act as reassurance. Literature reflects how fundamental is trust in patient-provider relation and how it should be framed within a voluntary decision-making process by both parties involved - thus, requiring a sense of autonomy - and interpreted within a framework considering the power and control issues that may arise (Hendren and Kumagai 2019).

Control perceived by patients with a chronic disease is also vastly influenced by social and environmental factors: job positions, socio-economic status or social support are the most critical determinants in this regard.

Studies have shown how the sense of autonomy is expressed through constructs "trust" and "control": both dimensions mutually interact in dialectical tension.

Control, patients' autonomy and trust are interconnected (McGeer 2008)]. The **experience of autonomy** is complex as well and includes other components, being the **control** a core component; the experience of autonomy for a given action, and a given agent, implies the authorship and ownership of the action and it is a compound of more basic experiences, among these, the experience of intentional causation, the sense of initiation and the sense of control. These require the sense of one's capacity for acting, self-narratives comprising pasts experiences and actions and projected future actions coherently unified, as well as motivation, awareness and introspection or reflection (Pacherie 2007).

Secondly, **the control's expression is intricate and involves the courage construct** – within it, the independency and autonomy -, **the information, the decision-making, and the social and environmental factors**. The courage as a construct relies on the idea of survivorship, sometimes accompanied by military terms and a strong sense of personal strength that may involve the rejection of condescending attitudes or pity, as well as the negation of the vulnerability. Control and courage are also linked to the engagement of individuals in advocacy and, if collective action is possible, activism.

Powerlessness as lack of control over own life seems to be an important mediating factor between social status and somatic health. A research conducted in 2009 (Dalgard, Bjørgulf Claussen, and Michael McCubbin 2009) showed how powerlessness was the only risk factor regarding the association between social status and somatic disorders, even adjusting by lifestyle factors. In this sense, the lack of control comprises several dimensions, such as sense of mastery, locus of control, self-efficacy and powerlessness. The lack of self-direction at work was also included in the research: as it has been explained in the section on Social epidemiology: , self-direction at work is a very relevant dimension of the social class.

Thirdly, the responsibility appears connected to control and courage; within *courage* emerged the independence and autonomy, also involving self-care and accountability[25].

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[25] The experience of autonomy is expressed through the persons' own personal strengths (CO31)(ED16) (EM09) (EM11) (EM13) (EN37), their positive self-perception, self-pride (EM08) (EM09) (EM12) (EM13) (EM16) (EN37)(EN41), cultural pride (EM08)(EM09) and their body-awareness or embodiment (ED8) (EM06) (EM08) (EM11) (EM16). To be in control implies to be responsible for theirs self-care including lifestyle changes (CO02) (CO09) (CO31) (ED16) (EN03) (EN03) (EN14) and medications(CO09) (CO31), including its adjustment (CO19) (CO31) (EN14), the of traditional remedies (EM08) or they abandonment/reduction (CO09) (CO20) (EM11). *Accountability* may be expressed through the normalcy and minimisation of the treatments burdens in their everyday life (CO20)((CO15) (CO31)or, even, as the liberation that to disclose the disease or condition implies (EM16).

Personality and age seem to be crucial determinants in responsibility. While age as co-determinant may be mainly related to socio-cultural factors, personality directly relates to the disease's self-management, jointly with awareness, the ability to set goals and objectives, and the coping strategies and acceptance of the disease. Some individual factors are socially co-determined: health literacy and the capacity to obtain information and self-directing informal education depend on several socio-cultural and economic factors. Research demonstrated that health literacy is determined by socioeconomic status and previous education (R. M. Parker and Ratzan 2019; Planas Coll and Casal Bataller 2003), ethnicity and racialisation, social support, language proficiency, social environment, communities and their values and norms.

As explained in the section on Health literacy, it is related to education, training and intuitive knowledge (‘common sense); health literacy is linked to proactive decision-making: both dimensions (literacy and proactiveness decision-making) appear insulated to the responsibility and accountability as a dimension of the autonomy after the diagnosis.

Figure 24 – Relation between health literacy, decision-making and psycho-social factors

Responsibility can also be interpreted in a non-adaptative manner, e.g., as guilt; guilt can be experienced as anxiety about work, guilt caused by the diagnosis itself or the prognosis, guilt expressed as inadequacy for not meeting the normative expectations at social and/or community levels, for being ‘needy’ or depending on others. Thus, **personality plays a major role in non-optimal adjustment to the living experience of the disease**; recent research proposing a model for analysing the patients’ personality in healthcare environments based on the Big Five (five-factor model of personality) stated that “Health Neuroticism is characterised by anxiety and stress related to personal health and health care. Health Extraversion includes the willingness to discuss health with close family and friends. Health Openness refers to the openness to change health routines and health practices. Health Agreeableness is characterised by the trust in physicians to receive optimal health care. Health Conscientiousness features self-discipline regarding health practices”. The anticipatory anxiety prior to counselling (neuroticism), the disposition to talk with peers about health (intra and extraversion), the willingness to change behaviours and adopt routines to the self-care necessities and the changing conditions (openness), the perception of his/her problems are being taken seriously by HCPs, and his/her confidence in the HCPs' skills (agreeableness), as well as the self-discipline for implementing habits and scheduling activities for reaching their goals (conscientiousness), would be related to an **adaptative sense of ownership, patients' autonomy and responsibility** (Martin et al. 2020).

The grief implies renegotiating the sense of the self; this is a needed step towards coping with the disease's consequences, both positive (growth opportunity, spirituality, validation) and adverse (unemployment or career, body image, stigma, impairments, disability). For instance, the ability to return to the employment after an acute crisis impact on the persons' functional outcomes, the significance and meaning issues, the renegotiation of the self and, also, the meaning that the work has for each one, in terms of social connections, self-image, identity and normality; of course, to return to work also impacts, positively, in the individuals' financial issues. It has been deeply researchers for cancer survivors and their adjustment between health and well-ebbing, functional status after the treatment, work demands, work environment and outcomes also considering their characteristics (age, gender, race, marital status, socioeconomic status and ethnicity) and the policies and economic factors underlying their reincorporation to work (Butow et al. 2020). Another meta-synthesis focused on Type 1 Diabetes in adults identified five factors impacting their adaptation and their return to work (disruption, construction of a personal view of diabetes, reconstructed self, living with T1D and behavioural adaptations): the synthesis showed how the early process of adaption is linked to the individual's self-identity, and both are determinants for their adjustment, facilitating to share more **'adaptative' strategies and behaviours** for **overcoming the conflict between their life's and the demands of the chronic disease** (Due-Christensen et al. 2018).

Patients' autonomy involves being active in making decisions, willing to discuss and expecting that the HCPs integrate their point of view and experiences, providing validation and generating emotional bonds. Literature shows aligned results; it is needed to integrate the living experience of the disease within the clinical practice, in a non-judgmental way the covert and overt manifestations and symptoms of the disease which are negatively impacting on the patients' wellbeing, quality of life, emotional and social health (L.-S. Parker et al. 2020).

The support from HCPs and from the social environment (including the family) during the time of the diagnosis has a crucial relevance in regards the acceptance but notably mediate the consequences of the disease; the access to knowledge and education and the emotional validation by HCPs and loved ones, social bonds, socio-economic status and material-environmental conditions appeared in the studies as relevant facilitators for the adaptation and the acquisition of well-tailored behaviours and self-management strategies.

Lastly, and linked to the health literacy as a facilitator of the patients' autonomy, the access to information appears as a very important sub-construct within the Control one, related to the patients' sense of autonomy, information, their access through ICT and devices availability (also mediated by socio-economic determinants), or academic or scientific literature (mediated by socio-cultural factors) or second opinions from professionals.

Sharing experiences and information with others is important for participants (probably related to its role in advocacy and increasing the disease visibility.

The paradigm shift from "evidence-based medicine" to "value-based medicine" also reshape the clinical outcomes preserving the autonomy of patients meanwhile reconciling the evidence and scientific research and clinical practice: the paradigm shift, although finding major barriers and reluctance, is re-emphasizing the importance of patients' preferences, choices, decision and the quality of life defined by themselves (Marzorati and Pravettoni 2017)

However, these perspectives may also suppose a reproduction of inequalities in accessing the health system and health disparities already in-place, 'washed' by the appearance of more ethical and person-centred care: it is needed that organisations and decision-making bodies consider the social determinants of health (Marzorati and Pravettoni 2017) and the current health disparities, as well as the systemic, structural and social, economic, cultural and environmental factors underlying for reshaping policies and, at the same time, ensuring equitable and fair access to healthcare and social support.

All of these factors facilitating or compromising the individuals' autonomy are partially conditioned by socio-environmental factors such as family support and social bonds, the individual's socio-economic status, and employment. The autonomy and the individual 'empowerment' is also mediated by the complex network of social determinants producing, also, health and social inequalities (Graham 2004; Graham, Kelly, and NHS Health Development Agency 2004; Marmot 2005; Whitehead 2007)

Section 5. The role of IT tools and the Internet

IT tools can be a valuable and useful tool for accessing information, acquiring non-formal and informal health education, self-managing health and supporting decision-making. However, some barriers appear to the technology use: the availability of appropriate connections and devices, the technological divide, and the socio-economic and material circumstances the most important ones.

The implementation of IT tools and the use of the Internet among particularly vulnerable populations encounter these specific challenges, being the co-creation and co-production and any other participative and community-focused approach, a feasible way to diminishing the access barriers.

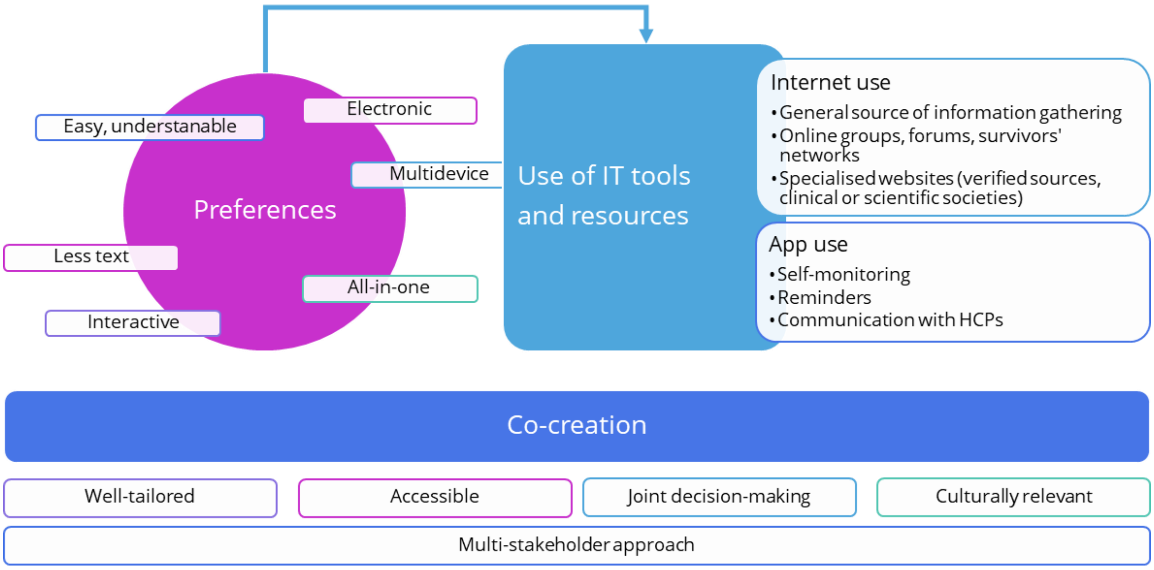

Figure 25 - General considerations for developing ICT tools aimed at underserved populations

Findings showed that access to information facilitates, even allows, a better decision-making; in addition, tools and apps support self-management and prevent **miscommunication, missed appointments or confusion** about meds, being easily and readily available. Some patients may also perceive that IT fosters their autonomy and feeling of control, being also able to foster self-awareness, awareness about the disease and supporting a positive behavioural change to more healthy habits.

The cooperative and shared decision-making aimed at self-management of chronic conditions between HCPs (in this case, nurses) and patients based on checklists and tracking of goals has been applied to diet, bladder and bower signs and symptoms of complications, physical exercise, skincare and healing of wounds, appointment reminders, medication reminders, maintenance and use of assistive devices or orthoses, home tasks, employment, physical or social rehabilitation, smoking cessation or healthier sleep habits in patients with lymphedema, diabetes, physical impairments and a wide variety of conditions (Dicianno, Henderson, and Parmanto 2017). The use of IT tools for Type 2 Diabetes and mobile apps' function was also studied, being mainly applied to self-monitoring of blood glucose, diet management, blood pressure, physical activity or weight tracking; some apps also include functions for logging and/or calculating insulin dosages. The function of analysing the logged data was present in the majority of applications. However, the cited systematic review showed that most of these apps were developed without involving their final users (patients with T2D) and without discussing or considering – at least, explicitly – health behaviour theories. At the same time, the currently available foundations cannot answer the most important concerns that the use of IT and mHealth raise as health interventions (Adu et al. 2018). Mobile applications were also revised for COPD self-management, encountering a vast range of heterogeneous interventions, with different devices, components, involvement of HCPs, frequency of measurements done by the users, thus providing unclear conclusions about the effectiveness of mHealth and COPD-specific apps compared with usual care. These apps measured physical function, QoL, physical activity, or dyspnea. (Shaw et al. 2020).

Multifaceted interventions, able to consider the bio-psycho-social context of individuals and the social, cultural, economic and environmental co-determinants of communities, are needed to provide more robust evidence on the processes' effectiveness for developing and implementing eHealth tools aimed at vulnerable individuals and groups. Internet is increasingly used as a source of health-related information and, so, a source of peer-support through online forums and social media channels; online groups permit the users to access to “multiple perspectives, the collective expertise of participants, the anonymity that reduces stigma, the similarity of participants, and convenience” in time and place, showing flexibility enough for keeping the engagement of participants. However, the sustainability overtime may be mediated by off-topic threads, lack of immediacy and anti-social behaviours of some users (Hu 2015). Still, the Internet would be a good choice depending on the connection, age, and IT literacy; for instance, it would be an option for persons in rural areas or areas lacking enough services and allowing greater flexibility. In fact, geographical coverage and proximity of the face-to-face group is relevant

Thus, **the tech divide should be considered**: the lack of Internet access, or a slow connection and the affordability of needed devices suppose a vital barrier. In addition, these tools, apps and even Internet access can be considered as a superfluous investment if individuals and communities are currently very deprived, marginalised and have no access to basic needs, such as housing or healthcare. The material circumstances should be carefully evaluated prior to developing and deploying IT tools or resources aimed at more vulnerable people. Some evidence suggests 'dissipating but significant effects' in terms of health out for underserved populations with T2D: telemedicine/telehealth interventions were paired with health educators' interaction – similar to in-person. The incorporation of a human component, the 1:1 or group-based interaction, was a very relevant element for engaging in the use of the IT tool and the patients' self-management through plans, alerts or reminders (Heitkemper et al. 2017); human-contact and power balance between providers and patients is an important step in creating IT tools (Palumbo 2016).

Another disadvantage is the problematic relationship that exists between HCPs and the information demands held by patients and frequently satisfied on the Internet: some HCPs are reluctant and advice to avoid going on the Internet, some patients perceive a lack of expertise in their HCPs of reference (in general, GPs) so turned to the Internet and, also, the Internet is used for self-diagnosing. Patients demanded more information and resources from HCPs, such as a list of trustworthy websites, more fluid communication, or training on searching, analysing and synthesizing information from the Internet. As previously examined in the sections of communication and health literacy, the covert contracts existing between providers and patients supporting the power imbalance may imply passiveness, no proactiveness and absolute compliance (Joseph-Williams, Elwyn, and Edwards 2014) as well as a presumption about patients and their inability for searching, analysing and selecting trustworthy information (e.g., in (CO08) or (EN32) among others) . The change from the medical model to the person-centred care may, on the contrary, enhance the importance of proactiveness, self-care, self-management and health literacy for participating in decision-making from an informed and autonomous place which will, ultimately, led to health-promoting behaviours (Simmons et al. 2014). The role of virtual platforms for enhancing communication and adherence appears in CO31: from the previous study, it worth to mention the potential fear of patients of being invasive for the doctor "might offend the doctor" through IT channels.

Lastly, IT tools and apps may have a suboptimal engagement; the co-creation, the consultation with the populations for developing and implementing IT tools is a feasible method for maximising the relevance, utility and user-friendliness of applications deployed, ensuring that these are well-tailored to the very particular needs, cultures, customs and preferences of communities and individuals targeted. Co-production and participative frameworks for creating technological solutions for chronic care have the potential of raising health outcomes, patient satisfaction, service innovation and cost-effectiveness (Palumbo 2016).

Literature shows that users’ involvement increases the adoption of the technology, the usability of the platforms and the adaptation to the end-users’ needs and requirements (Adu et al. 2018; Heitkemper et al. 2017; Palumbo 2016). The basis for developing applications, sites or, in general, technological aids for patients with chronic diseases should be the shared decision-making between developers, patients and health professionals (Adu et al. 2018) trying to overcome the potential HCPs’ hostility and the technological disengagement, and also their disengagement of healthcare, of some deprived patients (Palumbo 2016).

Co-creation relies on the interaction and engagement of all stakeholders at all healthcare ecosystem levels, fostering the cooperation and participation of HCPs – even managerial staff -, patients, civil society and IT developers; **while co-creation has been discussed for applications and software, online health communities have an essential role in co-creating the healthcare services through a ubiquitous provision and sharing of value, resources, information, experiences and emotional support** (Rezaeiaghdam, Watson, and Ziaimatin 2018)

Lastly, it should be noticed that data privacy, security, transparency and confidentiality matters are crucial for these collectivises. However, while the Internet helps reach highly reluctant users particularly preoccupied with security and confidentiality (Duncan, White, and Nicholson 2003; Shaghaghi and Aziz Sheikh 2011), most of the apps analysed in the systematic review by Adu et al., (2018) did not provide enough information about the data security and the privacy of the information.

RECOMMENDATIONS AND IMPLICATIONS FOR PRACTICE

Enhancing the impact of interventions in chronic health: a transnational qualitative meta-study on sampling, recruiting and communication with vulnerable populations

This chapter summarises recommendations and implications for practice, particularly useful for professionals and practitioners working on implementing person-centred healthcare, self-improvement in counselling, involved in the design and implementation of health literacy programmes and/or committed with vulnerable, hard-to-reach and disengaged communities and individuals. Please, notice that references to the sampled articles are maintained to facilitate the direct consultation of each study if the reader requires that. It is considered that simplifying the access to the studies outweighs the simplicity in reading the sections.

Chapter 5 is divided into seven different sections. Section 1 focused on counselling and patient-provider communication, also considering the intersectional aspects that should be envisaged. Section 2 is a summary of recommendations for the humanisation of care in-light of person-centred models aimed at empowered communities and autonomous individuals. Thirdly, health literacy is addressed in Section 3, providing recommendations for fostering patients' health literacy, disseminating information to society, and implementing programmes. Section 4 is centred on recruitment, places and means for recruiting and how the programme design impacts the recruitment and, then, the engagement of participants in health interventions and programmes. Section 5 is focused on self-management of health and how to foster these competencies in patients. Section 6 addresses the question of joint decision-making in healthcare and its ethical, social, cultural and systemic implications and factors. Lastly, the last section, section 7, is centred on communities and the implementation of healthcare innovations and the change of models and paradigms conducting to support their own empowerment.

Section 1. Recommendations for counselling and interpersonal communication between patients and providers

Basic recommendations on the amount and the type of information

Counselling can - and should - improve the patients' knowledge in an evidence-based and non-biased way about their conditions. The **need for information** seems as **vital** by a vast majority of the patients' samples in the studies consulted; to comply with their needs for information adequately, provide information gradually, and explain the consequences, side effects, **and prognosis**.

The curative/therapeutic objectives should be **discussed**, so **open communication** is needed in order to ensure **informed decision-making** (CO07, EN03, EM11). It is critical to support the conversation between **peers** (patients) and to promote the use of mutual support groups, health literacy programmes or the participation in patients’ associations; these are also considered a type of information delivery (CO26), which also has a significant impact on health outcomes. Informational needs should be met at the appropriate level for the individual, both technically and emotionally.

Some patients show greater information demands, for instance, breast cancer patients. Anticipation in providing the information to the patient is a good practice (CO10, CO15) and the role of "**information**" in the humanisation of care remains clear (CO10, CO11, EN23, EN32, ED8, EM12). Again, to recommend information sources and to **discuss side-effect and potential prevention measures** (CO08, CO10, CO11, CO13, CO14, CO15, EN40, which also provides valuable insight on the role of mutual support groups, or EM12, on Survivorship Consult, led by HCPs) is well valued by patients. In-line, to provide **impersonal information** should be carefully assessed (CO13), but, in this case, focusing "on processes related to the diagnosis and treatment" in order to "reduce anxiety and increase intention to adhere". The role of **impersonal information** in CO13 results relevant: the use of an **impersonal tone coupled with increased details** is associated with patient immediate post-visit reports of anxious preoccupation. To sum up, the CO13 concluded that:

> “the use of increased use of nominalization, concrete nouns, and group nouns may be an effective method of providing a more thorough and accessible explanation to

> patients. Additionally, providers could consider using impersonal language when discussing the tumor, procedures, recurrence, etc. Potentially, use of the impersonal may alleviate patient concern that her cancer is unique or challenging to treat as compared with other, similar breast cancer diagnoses".
>
> (CO13; p.8)

However, results should be taken cautiously considering the particular informational needs that cancer patients seem to require.

Patients may expect **high degrees of informational speech** from their provider (CO13, C019, CO27, EM12), particularly during the first stages of the diagnosis. Thus, **patients with higher informational demands attributing an important value to the information**, such as oncologic patients, would increase their health literacy even developing **research skills**[26] (CO08, CO20, CO22, CO27, CO31, EN37). On the contrary and depending on the settings in which the information is provided, the adequateness may mean "friendly, easy to read, clear and not too intricate", **direct** and **short** (CO22).

Patients demand **more research** (CO08), more skills for accessing research (CO08, EN04), and more **resources** adapted to specific situations (younger women in CO08, about the availability of interpreters for the CALD in CO12 or translation of materials in EN18; the trans-cultural issues in CO23, EM03, EN15; gender and racialisation in prostate cancer in African-American men in CO26). **Support for navigating the system** is required (EM04, EN24). Demands for **peer-based** groups appeared (CO31, CO36) and/or education (EN18). The role of associations seems to be too weak (EN39).

From an **ethical** point of view, information should be suited to the patient's health literacy, curiosity and must be accurate: medical terms and jargon may need to be **simplified** (CO22, CO29, EN05) or, most important, adequately explained: it means that information through counselling is not about simplicity rather than appropriate and detailed explanations when needed – for instance, excessive easiness may undermine the patients' ability for obtaining information by their own means.

To provide detailed information and accurate knowledge about the **prognosis is a good practice.**

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[26] should be said that, however, the meaning of "research" from the point of view of the patients remain unclear

The simplicity and lack of detail given to patients could be too much (CO22, EN01), highlighting the importance to adapt the terms and amount of information to the previous health literacy. A potentially sub-optimal health numeracy should also be taken into account (CO22, CO23, ED13). Lack of clear information appears also linked to the **dismissal** (CO08, CO27).

Patients' background and characteristics are crucial for determining which styles and communication cues are appropriate and the amount and complexity of the information provided.

Intersectional aspects and its impact on patients-providers relationship and communication

In line with the conclusions of a vast body of research, communication and counselling are modelled through the social determinants of health and health inequalities, culture, age, physical and cognitive functions, and socio-economic status appear.

Poor integration between the medical advice, the lexicon and language used and the daily life of patients and communities is observed (EN05), which is not easily attributable to patients' personal responsibility: for instance, unclear, abstract rules, lack of clarification of doubts may lead to misunderstanding, a poor adjustment to the disease, low self-management abilities and then, a poor prognosis (EN05)

Racialisation could run to undesired communicational situations; for instance, the lack of culturally aware care is also a barrier for communication, even for referring African-American patients to screening and/or preventive services (CO06). EN18, targeting the Hmong ethnic minority, emphasised the contradictory situation in which the responsibility on health outcomes is on the patient's side while the education provided is 0; it also highlights the medical model as the main aim of the visit. When dealing with migrants, the unawareness of knowledge by the HCP might drive to major health problems: patients interviewed in EM4 demanded to be listened ("*they [doctors] are deducing from what he thinks rather than what you are telling him*"). Disconnection between cultures and, also , the medical culture itself is also a problem (EM07). Besides, some questions viewed as "normal" and necessary from a euro/anglo-focused perspective might be felt as disrespectful. **Communication with CALD communities** and culturally diverse persons is a barrier: for instance, the mutual understanding might be overestimated (CO23).

Importantly, concerning the CALD communities and their language competencies, *chit-chat* and informal chat have a role in therapeutic communication (CO37) - being an essential factor in building relations, further explained in the next section. **Language barriers with CALD communities** might be problematic. Also, non-verbal cues need to be evaluated in cultural-specific contexts (EN02 EN35): so, EN02 highlights the importance of observing the "intersecting oppressions on health, access to care, and quality of life" and power imbalances in the therapeutic relationship - and, so, in the counselling, campaigns and patient education initiatives, as well as how these may impact on decision-making. As it states, "providers and organizations need to be aware of how marginalizing practices and social exclusion operate in structures and institutions, including health care, thereby shaping people's health care experiences and access to service". The potential reluctance in attending to the health services appears in several studies (among others, EN24, EM17).

The role of culture and, if required, the interaction between the destination and origin cultures, or the hegemonic culture versus the minority, should be carefully considered in this regard (Joseph-Williams, Elwyn, and Edwards 2014). Similarly, **differing cultural paradigms** might be overlooked (CO37). The effects of this misinformation with non-native speakers and CALD are also well-reflected in EN18: misunderstandings about the origins of T2D or the potential effects of medicines, or patients wondering about fundamental but unanswered issues appear, related to **compliance**.

In the case of CALD communities and, specifically, non-native speakers, the presence of minors as translators suppose two significant barriers in regards the clarity of the knowledge transmitted/received: the quality of the translation itself (e.g., ignorance of the terminology) and the refusal of children to **translate** some subjects should be considered as well (CO12).

In fact, communication and decision-making encounter two significant barriers in ***embarrassing* or sensitive topics**: while it seems to affect almost all patients, some culturally-diverse persons may find them particularly though - e.g, sexually transmitted infections, mental health issues, or end-of-life care.

Psychiatrisation (*hypochondria*) of women and harsh but paternalistic attitudes are present sometimes (CO08); this issue also appears in EM17 and, subtly, thoughout the studies about women. Besides, the patologisation of women and, in general, users of the mental health services is transferred to every situation (EN38). Perhaps, the **infantilisation** of women might also play a role (C008) as well as the infantilization of low-educated patients (EN23). Lack of information about sex (ED8) and assumptions about (hetero)sexuality of women (ED9) are present: these topics seems to be covered in a poorly way. Even in ED9, a participant explains how HCPs dismiss their concerns on testing because they are women who have sex with women. Nevertheless, it should be noticed that racialised men, also encounter assumptions about their sexuality (EM08), being these assumptions and prejudices deeply culturally ingrained (Kilty and Bogosavljevic 2019; Enck-Wanzer 2009; Malebranche et al. 2004)

Age, **physical** or **cognitive** functions are reflected in the quotations as important factors to keep in mind in interacting with patients (CO36). The impact of **severe material deprivation** is also reflected. Also, possible **self-stigma** should be considered.

Some measures could be undertaken. For instance, **safe spaces** may be crucial for providing adequate care and support to minorities and highly stigmatised communities[27], such as MSM with HIV or persons diagnosed with mental disorders. These places are also able to offer an alternative place for conducting mutual support groups and related interventions when individuals are reluctant to keep in touch with public authorities (e.g., irregular migrants).

Besides, the **continuity of care** is essential due to the trust-building needs; related to **trust-building**, some communities may prefer to have doctors “similar” to them (e.g., ethnicity, same condition, such as dyslexia, as mentioned in EN30). Lastly, face-to-face encounters vs electronic media preference depend on the target group (EN30, EM17). For instance, new arrivals and refugees seem to prefer female HCPs and face-to-face encounters (EM17).

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[27] More information about the persons’ perceptions about safe spaces can be obtained in EN19, EN02, EN38, ED12

Section 2. Humanisation of care and meaningful contributions: their role in counselling and health self-care.

Humanisation of care and inclusion of all **relational-psych-emotional aspects** appears linked to **decision-making** and, in particular, in playing an active role (CO06) and raising patients' **empowerment** (CO06). **Open communication raises the decision-making** and fosters the autonomy of patients (CO06, EM11). CO01, as a very conceptual rich paper, also emphasised the **fluid, honest, clear and reliable communication:** "They always told me the truth", related to the previous theme analysed. **To tell the truth** should be considered linked to **tact** and **warmth**. It leads to a relationship of trust and security between the HCP and the patient (CO01, CO06 CO10).

To be recognised as a person, by the surname and other aspects of the relationship, is detected as good practice.

To feel useful – them, **to provide a meaningful contribution to others** - could be a motivation for patients participating in peer-based programmes and research programmes (EN03, EN07, EN21 EN25, EN28, EN45, ED5, ED8, ED10, ED11, ED16, EM05, EM10, EM11 which interestingly mentions to serve as an example, to listen to others, to share, to overcome difficulties, and to help with quotidian tasks) or for caring significant others (CO10, EN03, ED7). It could also imply raising awareness and fostering patients' advocacy, linking this code with the empowerment of communities.

There is increasing awareness on the patients' competencies for managing, at least, the everyday routine related to their conditions; for instance, the Expert Patient approach, as well as the CDSMPS, already introduced in the conceptual framework, assumes that patients can self-manage their conditions in a more cost-effective way than at present. The EP also implies, to some extent, the appropriation of the medical knowledge, able to be integrated with peer-support groups, which may suppose an imbalance between caring and empowering. However, the romanticisation of the "appropriation of knowledge" should be handled with care. As long as the objectives and agenda behind are not entirely clear and the complexity of political, social and economic settings do not allow to unveil the whole picture (Greener 2008).

Section 3. Health literacy: recommendations, preferences and demands

Recommendations for fostering health literacy of individuals and communities

Patients **obtain** information from several and heterogeneous sources. **Friends** and the **Internet** are vital resources - particularly if the information is not understandable, not detailed enough, or insufficiently adapted to the patients' demands. **Associations** (CO01, CO26, CO32) are also a valuable source of information as well as survivors and **mutual support groups** (CO08, CO27, CO29, CO32, CO35, EM10, EM15, EN04, EN08, EN34). Online support groups are included and explicitly mentioned as been positive sources of information (CO27, EN04).

Mass media, DVDs or videos and books are other valuable source of knowledge for patients. **Specialists** and experts - through the second opinion - are a frequently mentioned mean for obtaining information if it is scarce. Sometimes, **online or face-to-face patients' groups** provide the evidence needed for looking for a second opinion.

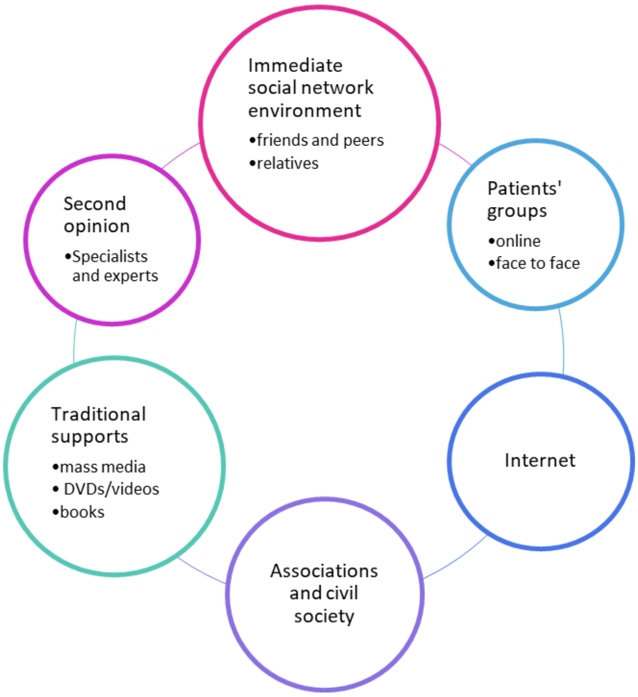

Figure 26 - Main sources of information

The **format** of the information - **graphics, charts, pictures and visual formats** - is also essential (CO04, EN34). Some patients may also expect **written information** (CO29). **Informational brochures** seem to have a substantial value (CO04, CO29, ED5). To inform about **websites** providing reliable and evidence-based information can be good practice for HCPs (CO08, CO22, CO3). **Mobile apps** could also be useful (CO31, CO32).

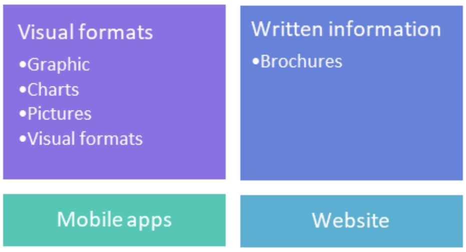

Figure 27 - Users' preferences

Individuals **demanded skill-building and more capacities and abilities** for accessing research (CO08, CO20, CO22, CO27, CO31, EN04, EN37), more **peer-based groups** available (CO31, CO36), more **resources adapted to specific situations** and health inequalities (CO08, CO12, CO23, CO26, EN15, EN18, EM03), support for **navigating the healthcare system** (EM04, EN24), **culturally-tailored information** access/ delivery (CO22, CO23, CO36, EN24, EM17)[28] and **training in effective counselling** aimed at improving the quality of the information delivered by HCPs (EN25, EN32, EN34).

Community's meeting points are relevant sites for delivering health literacy (rather than from, currently, obtaining that information): some examples are a local business - such as barbershop or pubs (CO26)-, health care infrastructures (CO26), churches (CO26) or fraternal organisations (CO26).

Disseminating information to the whole society

Information to the whole society about certain highly stigmatised diseases may **contribute to overcoming the discrimination** of persons with these conditions (e.g., VIH in EM16 or EN34)

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[28] Some examples or required resources for CALD communities are the availability of interpreters in healthcare settings, culturally-tailored concepts and definitions, the patients' preference for visual aids, the utility of story-telling techniques or the additional support that might be required for efficiently navigating the healthcare system

In regards to prevention campaigns, EN34 is a very interesting study: EN34, about HIV/AIDS, concludes that straightforward messages are ineffective ("*we have become immune to it*"). It would be more effective to address other aspects: social supports, general health and communication and general men's health. Informational assets should be easily accessible, bilingual (if needed), and culturally and contextually appropriate. Also, the contextual information about STI (Sexually Transmitted Infections), in general, is failing and is not reaching the adequate target, which is the high-risk groups (e.g., MSM); the appealing and the focus moved from the disease-centred approach to the specific behaviours are also interesting points to consider when implementing both, health programmes or interventions and health communication campaigns[29].

General recommendations for implementing health education programmes

A comprehensive set of recommendations for conducting and implementing health education programmes emerged from the studies.

Community settings is the critical frame in which analysing the integration of the views remains as the most important (EN08) (EN09) (EN25)(EN34). Other points for being considered are, for instance, the necessity **to engage local stakeholders** working on health and social services (ED12). Other ideas in regards the barrier that the transportation supposes are to provide participants with bus and parking vouchers could contribute to engaging persons living outside cities (e.g., in rural counties) (ED4), appeal to their desire to live longer (ED7), or to achieve a better QoL (ED7) for oneself (ED7) or for the loved ones (ED7).

Providing **opportunities to socialise** with other survivors and supporters/loved ones (ED07) (EM05) is important to improve the recruitment of participants. However, **complex socio-demographic, social and gender issues** in designing the programmes or adapting them (ED7) should be taken into account.

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[29] Interestingly, a lot of EN34 participants appealed to delivering shocking information, graphical contents can appeal to physical vanity, by using before and after pictures, or by exposing the side effects or protease inhibitors, also to provide attractive and interactive tools and methods in Internet for measuring the impact of living with AIDS/HIV in an intuitive way. Costs and other systemic factors of living with HIV could be used in campaigs, explaining how the lack of funds may affect the health care systems and the limited resources of HIV programmes. Another interesting result is that participants suggested to reorganise the information: info about STIs organised by sexual behaviours, instead of diseases.

If the programme is a standardised one, **to provide opportunities for knowledge exchange** between programmes implemented in different locations for peer-supporters and, if any, HCPs involved (EM10) would improve the recruitment of both, laypersons and HCPs (even decision-makers involved in the decision of its implementation).

* * *

At micro-level intrapersonal level, to **highlight the possible outcomes** and, if possible, **to provide insight into previous experiences and success stories** (ED12, ED14, ED15) is essential for reducing the drop-out. Some patients value positively the **intervention of HCP**s and more intensive assessment of progress, quantified (ED5, ED8). Also, providing **resources** (EN07) and **interesting contents** to the participants (ED7, ED19) is critical.

* * *

Information should be provided considering

- Its **accessibility**: information should be easy to find and readable, available and presented for different levels (ED7, ED16, EN01, EN18)
- Its **experiential and practical nature** (ED7, ED2, ED10, EN0, EN18)
- Its **practical dimension**, e.g., learning on coping skills (ED2, EN18) or diet alternatives, healthy but low-cost (ED7)

* * *

Snacks (ED4, ED5) or **incentives** (EN25, EN02) such as transport vouchers, can be important considering the programme's nature and the socio-economic environment and potential barriers related.

At the inter-personal level, cultivating **the *thelos* of the group** is critical (ED4, EN02). Dynamics should **consider the power balance between members** (ED10, ED2, ED4, EM05, EM15, EN02, EN19, EN34); **spaces should be safe and secure**, providing validation and acknowledgement of members' experiences (CO33, ED4, ED7, ED8, ED15, EN02). **Knowledge sharing** (CO33, ED2, ED10, ED14, EN01, EN18) and its meaningful dimension must be ensured as well.

At the organisational level, the **potential for adapting the programme** – thus, its flexibility (CO33, ED16, EM15, EN25, EN34) – and the role of leaders and facilitators should be observed: trainers and leaders need to be prepared for guiding new members, mediating in conflicts, offering and they could also alleviate suffering, anxiety and fear rapport (CO33, ED4, ED12, ED15, EM05, EM05, EM15, EN02, EN08, EN34); peer mentoring can be enabled if required (ED10). Thus, the continuity of the intervention, thus the long-term support after the end of the programme itself, appears as a very important factor for reducing the drop-out (ED16, EM05, EN02) linked to building sustainable and long-term structures for communities.

Table 33 - Specific recommendations for Internet-based groups and face-to-face intervention

Internet-based groups	Face-to-face
- anonymity and confidentiality (EN07) - to down the emotional barriers among users (CO33), - geographical barriers (CO33, EN07 - more frequent communication (CO33 - discussion in detail (CO33) - express thoughts more clearly (CO33)	- to receive non verbal cues and relevant body language (CO33, EN08) - be more willing to share stories and personal information (CO35, ED4, ED12). - **appropriate transportation** and **distance** (ED4, ED5, ED16, EM17)

At the community level, and considering their **values, norms**, but also their **discrimination, stigmas or current societal conditions and inequalities**, to consider **gender** and **culture** is critical: gender mediates the use of Internet-based groups (CO33, ED5, ED14) and affects priorities and roles, that may enter in conflict with the attendance, such as caregiving (ED14).

For conducting successful culturally comprehensive interventions, it is required to **ensure linguistic accessibility** or bilinguals, if the members are not native speakers (EM04, EM17, EM18, EN0, EN35); story-telling and narratives are a valuable tool for CALD (CO35). It is essential to raise the companionship (eg., sister or brotherhood) and, also ,to find mediators and facilitators similar to the group and, at best, peers (ED5 ,ED7, ED8, EM02, EM05, EM15, EN18); it is linked to empowerment and validated racial identity (EN02, EN34). The role of relatives may be important for some minorities, such as Latinos (EN01). Snowball recruitment can be particularly successful for CALD (EN01).

At the macro-level, **policies able to tailor care and change life conditions impacting at the decision-making le**vel (EN02), as well as advocacy and policy-aimed strategies (EM05, EN02, EN19, EN25, EN34), appeared[30].

* * *

<u>Key recommendations for health education programmes</u> (regardless are led by peers or by professionals) in order to foster engagement and reducing the drop-outs while enhancing the conversation and participative dialogue are:

Figure 28 - Critical factors and recommendations for health education programmes

- **Clear expectations**: The expectations and nature of the programmes implemented should be clear
- **A common *thelos***: cultivating the thelos within the group
- **Power balance**: To ensure an internal dynamic and sense of power balance. In line with the ED10 recommendations, it may be needed to pull in quiet members, toning down the gregarious and dealing the negative presences.

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[30] however, these factors might be out of the control of the recruitments and programme coordinators

- **Sense of safety:** Safe places are crucial for implementing sustainable interventions for hard-to-reach and highly stigmatised populations (ED10, EM02, EM15, EM17, EN02): the safety is even more relevant during the implementation and the conduction of the groups than during the recruitment. However, and as long as participants share sensitive or personal information, ensuring safety (extrinsic) and feeling safe in the group (intrinsic) is needed to ensure fruitful participation.
- **Cultural sensitivity**: even, interventions, programmes and groups should be tailored to each culture. Particular sensitive issues (e.g., mixed groups) must be taken into account for conforming and planning the programme. Besides, for CALD, bilingual information may be needed. Tokenism is both a barrier and a risk (Beales and Wilson 2015).
- **Adapted contents and materials:** the content of the programme and its format should be adapted to the backgrounds of the target groups, which may involve social, cultural, ethical, even economic settings. It also minimises the risks of power imbalances between participants. To tailor the progress and the scope to individuals' needs, providing safe spaces, a cohesive, committee-based leadership, similar socio-economic backgrounds or circumstances and a multi-component effort is crucial for ensuring institutional and interpersonal reinforcement and support. Attractive didactic materials, even to have films and audio-visual materials, preferable for certain groups, are more engaging and facilitate following the course contents and learning meaningful information and skills. Additionally, films and storytelling allow a comprehensive reflection of members' emotions.
- **Involve HCPs or promote mutual support**: some programmes may work better if peer-based and others will perform optimally through the participation of HCPs. If the programme is not yet validated or tested in similar settings, a map of stakeholders and some social marketing and local research may be needed. In short, sometimes, participants value the professional advice for ensuring that the info is reliable/trustworthy and the regular monitoring (*quantify myself*) that the presence of HCPs provides; in other target groups, or other occasions or settings, these two factors may be deterrent.
- **Time and costs** must be considered; however, these costs should be evaluated in terms of cost-efficiency. Difficulties for obtaining funding should be considered, too (Beales and Wilson 2015). **Time and costs for**

participants are even more important as long as they may be underserved persons, then special consideration should be given regarding the travelling times and transport types available, costs, caregiving and job obligations, among other quotidian issues.

- **Additional skills training can be fruitful for peer supporters**, even some basic concepts on psychology, motivation, etc.
- **Keeping the motivation up:** To promote peer experiences sharing in order to aim for results by viewing the results of others: to see results (in one's health or in others') is a powerful motivation.
- **In sum, most important factors are the adaptation and flexibility**. Flexibility also applies to adaptation to different places, as explained in ED12: the initial intervention, homogeneous, was adapted on the go for a better fit in the particular sites; further, the intervention and the ways for conducting it impacted on the mentors, mentees and nurses involved, because of its implicit political nature.

Section 4. Optimising the recruitment by the community-centred approach

Where to recruit

Health disparities (defined as differences in health outcomes) are connected to different disadvantages: lack of access to information and services (including the health ones), inappropriate transportation, even isolation, limited literacy and poor education, violent neighbourhoods, lack of parks, community centres and sports facilities, scarcity of groceries and supermarkets with fresh products available and affordable, socio-cultural and ethnical discrimination, socioeconomic exclusion, stigma, lack of social networks and support, inapposite policies on health and education, insufficient funding of health and education, inappropriate housing, psychical suffering, weight stigma, marginalisation of LGBTIQ+ persons, and so many more factors that may negatively impact on health (Graham, Kelly, and NHS Health Development Agency 2004; Schiavo 2014); the analysis of community-specific health disparities and how the macro-level dimensions interacts in the meso and micro-levels are complex, thus the strategies in the fields health communication and health literacy should be **community-centred, well-tailored, culturally and linguistically appropriate and aware of all health disparities and the impact of social inequalities in the individuals' outcomes, possibilities and needs** (Schiavo 2014).

Hard-to-reach may result in stigmatising people as "unavailable" for the research or for engaging in health education programmes. It should be noticed that populations often categorised into hard-to-reach or hidden categories are, among others, those being under social pressure of the broader community, faith-based communities, persons fearing the confrontation with legal authorities or migrants. Also, persons living in remote locations, in vulnerable or deprived social and economic situation, over-researched groups and persons those who have no interest to be found or contacted might be hard-to-reach as well.

Complex socio-demographic issues to consider when adapting or designing the programme are directly related to the main audience and the difficulties they may face, apart from their health problems: for instance, the age range and the socio-economic necessities (e.g. "*The 20 to 30 age range is a bad range. They're [Black men] still trying to find themselves. Oftentimes they're working jobs with no* *benefits, including health insurance to cover doctor's visits*" (ED7)). Also, complex socio-demographic issues may be related to stigma: it can be particularly tough to recruit persons in highly stigmatised populations (e.g., irregular migrants, persons with STIs, sex workers, prisoners and ex-prisoners, etc.). These complex situations also affect the communication prior to and during the recruitment.

Figure 29 - Most important recruitment methods

In continuity to the above-mentioned role of the community, a non-exhaustive list of places or facilities for recruiting persons in order to establish health literacy programmes or MSG is provided, empathising the local community and mediate environments: **local health and social care entities, including GPs and, in general, HCPs, to recruit through community events and facilities, including churches, sororities/fraternities, barbershops or salons and, also, peers through word-of-mouth, given the roles that trust in the recruiter plays during the early engagement**.

Whilst there may be exceptions, Internet-based campaigns seem to be less effective than offline ones in enrolling volunteers who keep participating in follow-up questionnaires. For instance, offline campaigns may be more effective for cohorts, providing a better follow-up engagement (Bajardi et al. 2014). Then, to know the community by showing genuine interest in them is critical before selecting which means would work (Shaghaghi and Aziz Sheikh 2011). The vast majority of methods are face-to-face based, but the role of the Internet remains unclear. The Internet can be used as a mean for conducting interviews without involving abreactions or highly charged emotional reactions. In addition, Internet may be also useful for reaching highly reluctant users concerned about privacy (Duncan, White, and Nicholson 2003; Shaghaghi and Aziz Sheikh 2011).

The programme design and needed adjustments for improving the recruitment results

Firstly, the format may be important:

- **Internet-based groups**, while show certain limitations, also offer a different way for intimate: the anonymity and confidentiality (EN07) suppose to down the emotional barriers among users (CO33), also the geographical barriers (CO33, EN07) permit more frequent communication (CO33), a discussion in detail (CO33) and express thoughts more clearly (CO33)
- **Face-to-face,** instead, allows receiving non verbal cues and relevant body language (CO33, EN08), facilitating a more “profound” connection with people. Also, service-users would be more willing to share stories and personal information than (sometimes pessimistically) expected (CO35, ED4, ED12). **Transportation** and **distance** to the venue in face-to-face interventions is relevant (ED4, ED5, ED16, EM17)

To **highlight the possible outcomes that** may increase retention, these should be adapted to the target group (ED12, ED14,ED15): these outcomes must be relevant for them (e.g., endurance, stress reduction, feeling of control, overcoming addition, in ED15). Other patients value positively the intervention of HCPs and more intensive assessment of progress, quantified (ED5, ED8). Inline, a systematic review identified the motivation and willingness are the significant facilitators for engaging in peer-supported interventions **and being benefited from them; in fact, there may be a selection bias in some reviewed trials**: persons who accept to participate in the studies are more favourably disposed to the intervention and may have higher interventions (Dale, Williams, and Bowyer 2012)

Secondary gains should be studied: the validation, positive feedback, group's confirmation and acknowledgement of their achievements and the socialisation could be a motivation for engaging in the programme (CO33, ED4, ED7, ED8, ED15, EN02). Payments or more direct incentives are mentioned (EN25, EN02). It might imply having more resources available (EN07)

Leaders and facilitators' role seems to be crucial for guiding new members, mediating in conflicts, offering and alleviating suffering, anxiety and fear rapport (CO33, ED4, ED12, ED15, EM05, EM05, EM15, EN02, EN08, EN34). To enable peer mentoring is an effective strategy for sustaining groups while balancing the roles (ED10) and facilitating long-term contact between participants involved to provide support over time and continuity (ED16, EM05, EN02). The advocacy and policy-aimed strategies would be an essential facilitator in engaging members (EM05, EN02, EN19, EN25, EN34); for instance, in EM05, the advocacy of involved men in prostate cancer awareness is a factor for building a group identity and a constructive sense of self at the group and individual levels. In EN02, EN19, EN34, peer-based methods and programmes appear firmly focused on advocacy and activism for policy change.

Contents are highly relevant (ED7, ED10): for instance, patients may prefer to learn about side-effects, psycho-emotional management abilities, and information shared by peers concerning everyday life (ED2, ED10). Knowledge sharing is vital (CO33, ED2, ED10, ED14, EN01, EN18). How contents are provided matters: accessibility, information easy to find and readable, available and presented for different levels (ED7, ED16, EN01, EN18), experiential nature (ED7, ED2, EN0, EN181) and learning on coping skills (ED2, EN18) Snacks (ED4, ED5) could be an excellent opportunity for demonstrating that healthy foods are also yummy. Also, diet alternatives, healthy but low-cost, are an interesting topic (ED7)

Culturally comprehensive interventions could raise CALD communities' empowerment; bilingualism is almost a universal topic covered by studies focused on non-native speakers or including them (EM04, EM17, EM18, EN0, EN35). For instance, in CO35, some participants said that the "culturally-comprehensive" intervention (the Diabetes Empowerment Programme) changed the way they interact with physicians (e.g., a doctor told a woman, during the role-play, that she was being aggressive or harsh): story-telling and narratives were an effective engagement tool for African-American persons with DM2 (CO35). In EM02, emphasis on young men’s leadership, skill-building and social bonds (including familiar ones); EM15, also relevant in masculinity and CALD fields, highlights the role of brotherhoods and social bonds among men; it even impacts on skills building and learning of constructive coping skills. In ED5, *Promotoras* (Latinas) are very well considered by attendants: it is essential to raise the companionship (e.g., sister or brotherhood) and, also , to find mediators and facilitators similar to the group and, at best, peers (ED5 ,ED7, ED8, EM02, EM05, EM15, EN18). The importance of gendered elements (the verbal element) in CALD communities is also highlighted in EM17, which also crossed CALD women's age. For its part, EN01 emphasises the role of relatives already involved, thus the snowball recruitment. EN02 proposes an engaging peer-based programme aimed at, at medium-term, tailoring care and changing policies and decision-making. It is also highlighted in other papers already cited above. The cultural adequacy and empowerment could lead to an enhanced or, at least, validated racial identity (EN34). Peer-based support offers a safe space to disclose sensitive information. Health literacy, engagement and empowerment appeared strongly linked.

Other facilitators identified are the promptness in access (explicitly mentioned inED4), and also **the continuity of the intervention outside the meeting venues**: for instance, to have homework, diaries or written handouts (ED4).

Section 5 Fostering the self-management and the proactiveness in patients' health

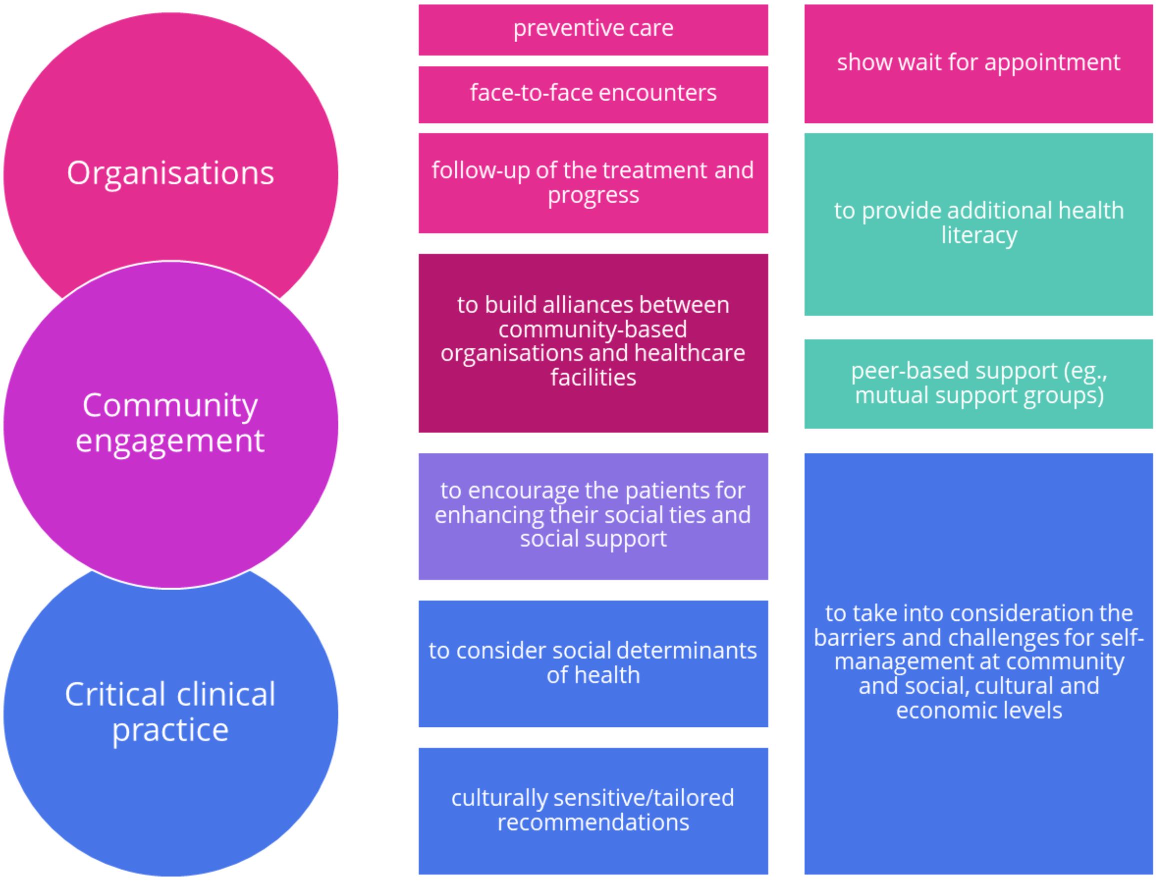

Figure 30 - Factors contributing to raise the proactiveness of patients

At the organisational level, to provide preventive care, ensure a show wait for an appointment, and promote additional health literacy in peer-based or any other form of health education programmes will strengthen the self-care and self-management skills of patients. Also, **to record and follow the treatment and progress** may enhance the patients' self-management competencies (CO19) (ED13) (ED6) (ED8) (EM08) (EM12) (EN29) (EN45) as well as the **alliances between community-based organisations and healthcare facilities** (CO26) (EM08) (EN01) (EN19) (EN24). **Social ties and social support** are critical for all patients but crucial for the most vulnerable individuals (CO08) (CO35)(ED13) (ED14) (ED6) (ED8) (EM08) (EM09) (EM10) (EM13) (EM16) (EN14). In general terms, at the organisational level,

face-to-face encounters are preferred in terms of adherence (EM17) (EN05). The social networks and support also impact in this regard (CO06) (EM06) (EM08).

* * *

Self-management barriers and challenges at the community level may appear due to **not culturally sensitive/tailored recommendations** or inappropriate messages (CO06) (CO12) (CO23) (CO37) (EM04) (EM07) (EM17) (EN18). **Cultural differences** should be taken into account. It should be noticed that adopting healthy dietary patterns sometimes will include to re-adopt the CALD's traditional diets. The re-adoption of the CALD traditional diets may be a way for culturally-tailoring care, supporting their process of building a strong identity at the same time that reducing the risk or mitigating the effect of Western Diseases (Lindeberg 2010; Lipski 2010; Truesdell et al. 2018)

The role of the **family** in highly *familistic* cultures, such as Latinxs or Hispanic groups – including Spaniards – should always be integrated into the health care (CO06)(CO08) (CO37)(ED14) (EM04) (EM08) (EM10). **Faith** or **spiritual** practices can be an effective vehicle for promoting self-care (EM04) (EM08) (EM13) (EM16) (EN01) and promoting self-management behaviours and a healthier lifestyle (Janssen-Niemeijer et al. 2017; Permana 2018); although faith might be also a barrier, leading to resignation and reducing their motivation for making changes in their lifestyle to manage a chronic condition (EM07) better.

Section 6. Joint decision-making in healthcare

Joint decision-making is a necessity **to move forward from traditionally and illness-centred attention to person-centred healthcare**, raising the involvement and engagement of patients in their own health journey, safeguarding and respecting their rights and autonomy and fostering the communication and information exchange with healthcare professionals (Edwards, Davies, and Edwards 2009). While this process may encounter reluctance from both sides, HCPs and patients themselves, it is in-line with the ethical standards that should sustain the clinical practice. The rigorous and informed analysis of power differentials in counselling and medical treatment, the critical examination of major inequalities at social and historical levels, and the ultimate aim of enhancing the physical, mental and social health of all patients are the major foundations for critical clinical care and healthcare policymaking.

Firstly, information is the needed first step for convincing -rather than persuading – patients for following and adhering to treatment (CO13) (CO07) (CO29) (CO38) (EM11) (EN23): in order to avoid persuasive or coercive communication, the information about the disease, the prognosis and the treatment choices should not be *excessively* focused on the persons and their lives, family obligations or any other personal and sensitive private issue (CO07) (CO13) (CO22) (CO29)(EM11) (EN09); to provide information in an **impersonal**[31]way implies to focus on facts and processes (CO02) (CO07) (CO13)(CO14) (CO29) (EN32) (EN36), explicit recommendations (CO07) (CO29) (CO38) (EM11) (EN06)(EN32) and to **offer diverse options** to patients (CO13) (CO27) (CO31) (CO38) (ED16) (EN09).

Secondary, all manipulation or subtle persuasion techniques that might undermine the patients' autonomy should be avoided. Thirdly, the information provided should be accurate and proportionate to the patients' demands, health literacy and general literacy, and the decision-making process's necessities. Very brief and vague information (CO07) (CO08) (CO09) (CO23) (CO26) (EM08) (EM11) (EN39) (EN40), **over-simplification** (CO26) (EM06)(EM08) (EM11) and **overwhelming** information (CO31)(ED1 6)(EM11) (EM12) should be averted, as long as these can cause confusion, misunderstanding, indecision and frustration, even guilt. To overtly show

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[31] Interestingly, providing the information in an impersonal tone can enhance the sense of control of the patient by "not personalising" the health problem and its prognosis. However, there are more appearances during the study on the importance of validation and emotional support.

‘negative’ reactions to patients’ **disclosure** (CO15) (CO20) (EM11) (EM17) (EN14), dismissing the patients’ experiences (CO20) (EN01), **to accuse patients** (EN14) (EN24), **to engage in harsh confrontation styles** (CO01)(EM11)(EN10), to provide sensitive and challenging information in an *excessively direct* way, ‘**without hedging’** (CO07)(EN33)(EN40), and **condescendence** (EN02) (EN23) are significant barriers.

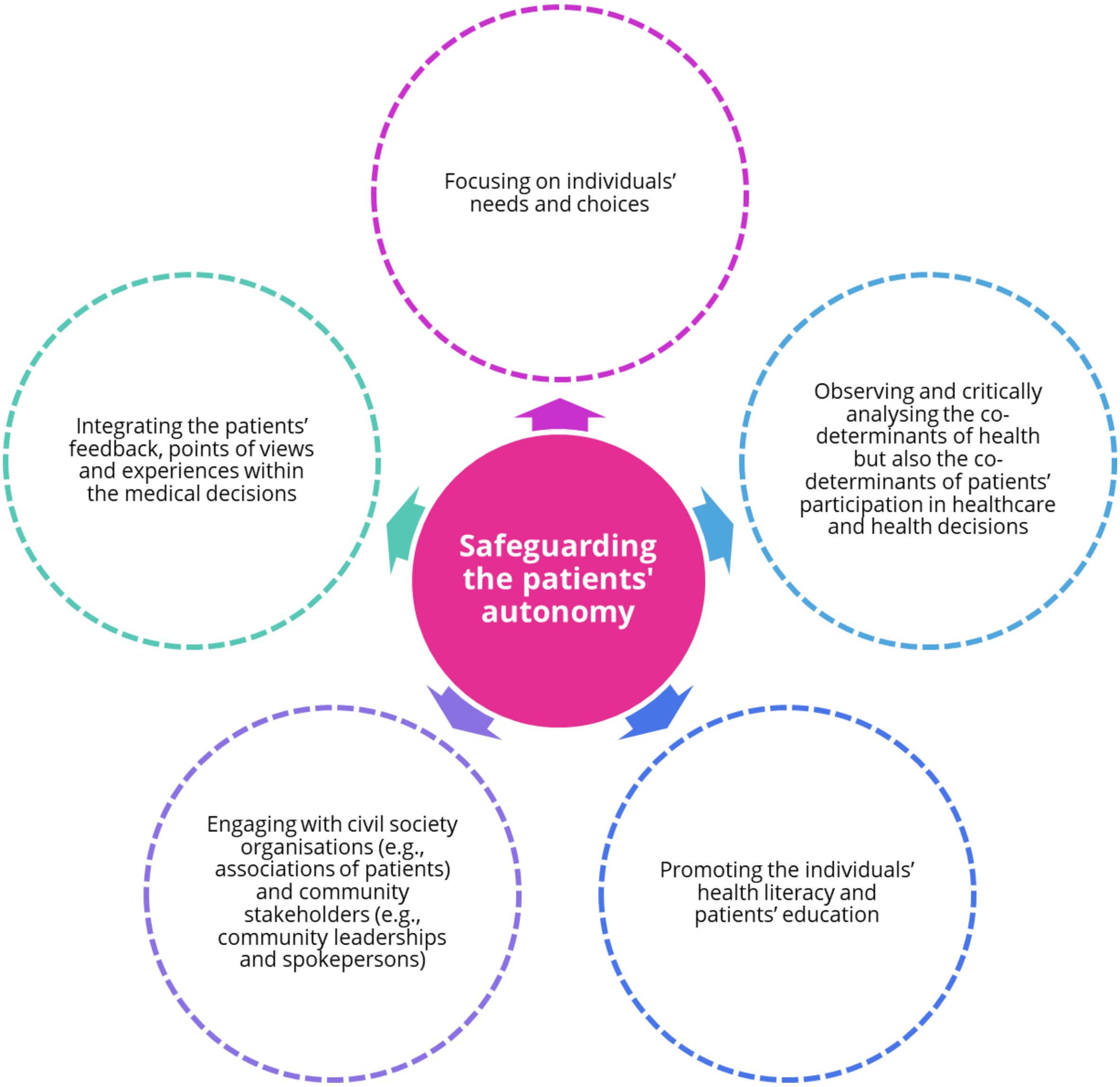


Figure 31 - Key factors involved for safeguarding the patients' autonomy

Lastly, adjacent factors to be considered are the time devoted to the decision-making process within the counselling (EM04)(EM11) (EM12)(EN15)(EN23)(EN32) and the role of the immediate environment, relatives and family (EM06) (EN32)

(ED16); both are critical factors to arrange prior to establishing an effective and respectful decision-making process focused on the patient as a whole person.

Person-centred care requires joint decision-making and autonomous patients, making choices, participating in their own healthcare, and expressing their health needs, priorities, and expectations. Thus, **decision-making should be focused on the patients and, also, considering macro-level settings, thus social, cultural, economic and environmental determinants as well as structural and systemic conditions, including the historical factors that may be related to the current communities' and individuals' circumstances** (Gethin et al. 2020).

Patients' autonomy can be safeguarded by

☑ Focusing on individuals' needs and choices
☑ Observing and critically analysing the co-determinants of health but also the co-determinants of patients' participation in healthcare and health decisions
☑ Promoting individuals' health literacy and patients' education
☑ Engaging with civil society organisations (e.g., associations of patients) and community stakeholders (e.g., community leaderships and spokepersons)
☑ Integrating the patients' feedback, points of views and experiences within the medical decisions

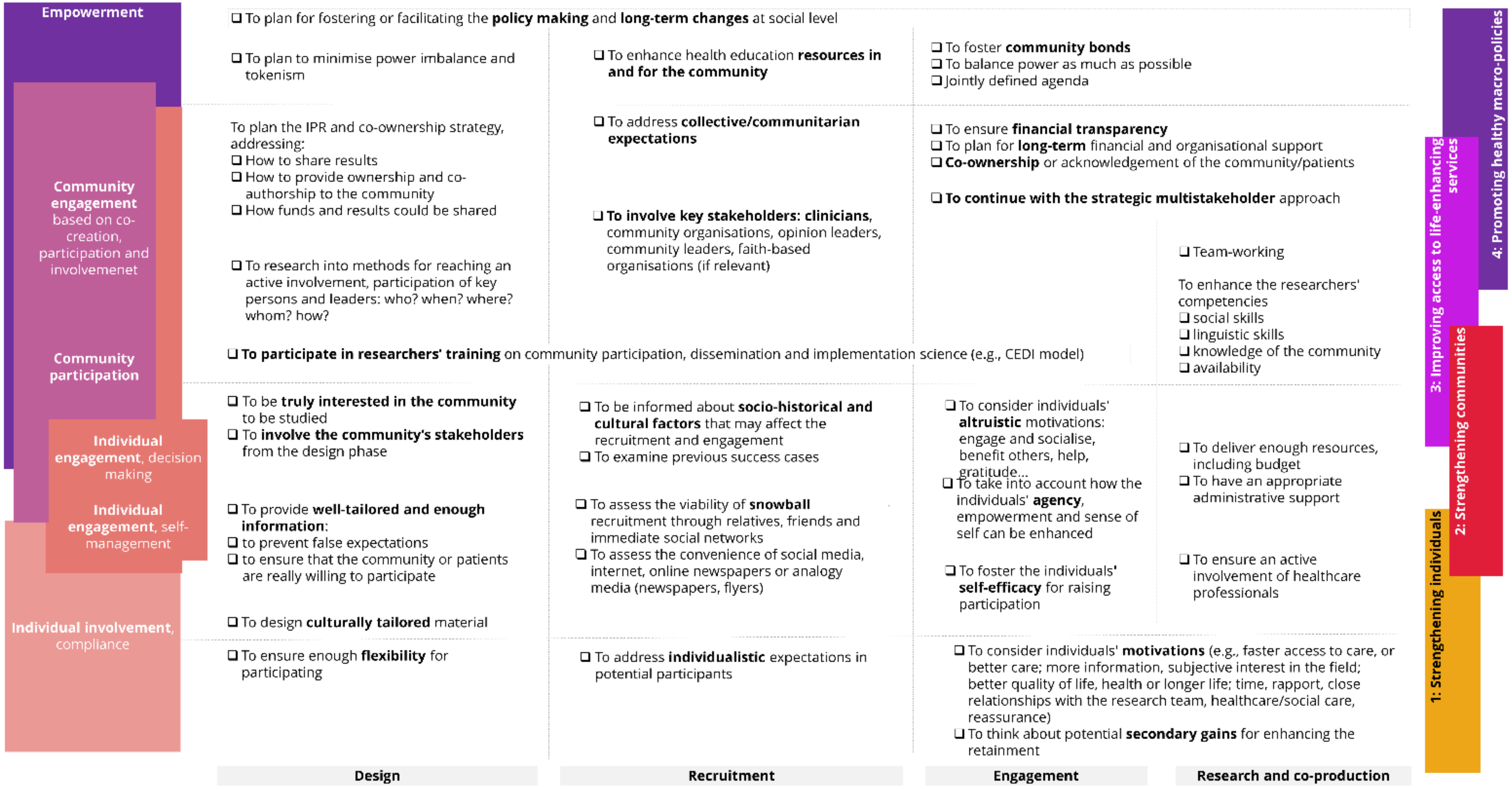
Literature and the studies revised show similar results. The lived experience of patients must be integrated into the clinical practice (L.-S. Parker et al. 2020) and patients' choices, preferences and voice-choice should be respected. The autonomy reached by the patients positively impacts their quality of life, as defined by themselves (Marzorati and Pravettoni 2017) but always without ignoring the structural factors that are underlying these decisions and the policies guaranteeing the person-centred care. In sum, the objective is to pursue fairness, equality and access to healthcare and social support.

Section 7. Healthcare and empowered communities

The implementation of co-production methods during the whole health innovation process, community-based research or any other process requiring the engagement of underserved, traditionally discriminated, or vulnerable communities could offer a more tailored process and more successful recruitment, raising the recruitment and retainment of disengaged groups and individuals. It is needed to engage participants, advocacy entities and community stakeholders at the long-term.

The following checklist, in Figure 32, summarises findings translated into best practices, divided into the phases of the design and execution of a person-centred co-production

Figure 32 - Checklist to promote community empowerment and individuals' engagement in the design and implementation of new services and care models and in healthcare innovation or research for person-centred care



☐ To plan for fostering or facilitating the **policy making** and **long-term changes** at social level

☐ To plan to minimise power imbalance and tokenism

☐ To enhance health education **resources in and for the community**

☐ To foster **community bonds**
☐ To balance power as much as possible
☐ Jointly defined agenda

To plan the IPR and co-ownership strategy, addressing:
☐ How to share results
☐ How to provide ownership and co-authorship to the community
☐ How funds and results could be shared

☐ To research into methods for reaching an active involvement, participation of key persons and leaders: who? when? where? whom? how?

☐ To address **collective/communitarian expectations**

☐ **To involve key stakeholders: clinicians,** community organisations, opinion leaders, community leaders, faith-based organisations (if relevant)

☐ To ensure **financial transparency**
☐ To plan for **long-term** financial and organisational support
☐ **Co-ownership** or acknowledgement of the community/patients

☐ **To continue with the strategic multistakeholder** approach

☐ Team-working

To enhance the researchers' competencies
☐ social skills
☐ linguistic skills
☐ knowledge of the community
☐ availability

☐ **To participate in researchers' training** on community participation, dissemination and implementation science (e.g., CEDI model)

☐ To be **truly interested in the community** to be studied
☐ To **involve the community's stakeholders** from the design phase

☐ To provide **well-tailored and enough information**:
☐ to prevent false expectations
☐ to ensure that the community or patients are really willing to participate

☐ To design **culturally tailored** material

☐ To be informed about **socio-historical and cultural factors** that may affect the recruitment and engagement
☐ To examine previous success cases

☐ To assess the viability of **snowball** recruitment through relatives, friends and immediate social networks
☐ To assess the convenience of social media, internet, online newspapers or analogy media (newspapers, flyers)

☐ To consider individuals' **altruistic** motivations: engage and socialise, benefit others, help, gratitude...
☐ To take into account how the individuals' **agency**, empowerment and sense of self can be enhanced

☐ To foster the individuals' **self-efficacy** for raising participation

☐ To deliver enough resources, including budget
☐ To have an appropriate administrative support

☐ To ensure an active involvement of healthcare professionals

☐ To ensure enough **flexibility** for participating

☐ To address **individualistic** expectations in potential participants

☐ To consider individuals' **motivations** (e.g., faster access to care, or better care; more information, subjective interest in the field; better quality of life, health or longer life; time, rapport, close relationships with the research team, healthcare/social care, reassurance)
☐ To think about potential **secondary gains** for enhancing the retainment

The community participation and co-production role depend on their capacity for producing a real and long-term change conducting to meaningful empowerment of disengaged and/or disenfranchised groups, therefore paving the way to more efficient person-centred care. There are some important considerations to foster person-centred care through the engagement and empowerment of individuals and communities.

On the one hand, as previously explained, at the individual level, offering flexibility and fostering self-efficacy ensures safety and confidentiality are key aspects. Furthermore, engaging participants, raising their confidence, adapting terms, and overcoming tokenism are essential to empowering vulnerable communities.

Likewise, to prepare specific, well-tailored and appropriate information addressed to individuals and communities to be involved, founded on a community's sound knowledge, is required.

Vital factors are to tackle the **power imbalance** during the early stages, involve health professionals and key stakeholders during co-creation processes, and build **trust**. Trust and acknowledgement of community contributors are decisive during the design and recruitment stages, also during the execution phases. The acknowledgement of their contributions, even co-ownership if it is possible or pertinent, can be considered.

To consider the **latent disengagement** and which means and **alliances** may help to overcome the **reluctance**, the communities' need for **structures**, and the establishment of **long-term bonds** for **supporting these communities in their own process of empowerment** at practical and tangible levels are decisions that should be taken and discussed with the main interested parties: the persons that will be benefited, or damaged, by the intervention or the innovation. It should be noticed that the objective is not *empowering communities*, rather than supporting them through different means (providing resources, facilitating the policy-making, providing contacts and networks ,etc) in their ***own*** process of empowerment. How social, cultural, economic, and environmental settings might impact the communities' participation, engagement, and empowerment should also be thought from a critical, historical, **and societal-aware perspective**

CONCLUSIONS

This dissertation addressed the question about the communication in counselling, the role and possibilities for health literacy and the access to information, the self-management and the factors integrated within the decision-making process, the relation between patients' autonomy, community empowerment and societal and political changes, and, transversally, the challenges that technologies and eHealth suppose for deprived and highly vulnerable populations.

Structural mechanisms are underlying the patients and communities' difficulties and disparities in health communication and, also, in accessing information and education about health, which have an effect in decision-making, self-management and health outcomes.

All these aspects were analysed framed within the **socio-ecological model** and integrating within the analysis an intersectional approach able to consider different co-determinants of health, health communication and access to health care and health literacy. Each factor and co-determinant interact with each other and are inter-related with the structural conditions and material circumstances at social level.

Education, gender and sex, race, ethnicity and culture, material deprivation, age, physical or cognitive functionality and public policies were the most important factors unveiled during the research: its influence and impact are ingrained at macro, structural level (also including the physical and cognitive function within the structural analysis, impacted by the ableism and mentalism within the healthcare system and, in general, the social field). However, some individuals' co-determinants also arose: self-efficacy, motivation and personality have shown an essential impact on communication, health literacy, engagement in health education programmes, self-management or decision-making; however, it should be recognised how these individual/psychosocial factors at the micro-level are deeply influenced by communities' settings and also by structural or systemic conditions.

I.

Communication in counselling depends on the informational exchange but, importantly, the relational development. Information is a critical factor in fostering the patients' autonomy and promoting their ability, skills and competencies in decision-making, but the information also supports the trust-building process and the therapeutic relationship. To provide sufficient information, accordingly with the patients' informational demands, and to pay attention to the communication style and skill-building, there are two important factors for fostering the patients' disclosure of key information, trust, autonomy, and proactiveness and disposition to self-care.

Power imbalances are considered within the fundamental research; in this context, the 'power' reflects the patients' abilities for participating in counselling and making decisions about their own self-management journey and their treatment; conversely, power imbalances in the relationship between providers and patients may be reflected in 'covert contracts', pre-assumptions and expectations from both sides: medical authority, power and credentials/knowledge interacts in the medical consultation within the traditional medical model. While the term 'empowerment is, in general, not used in individual settings, the patients' power may refer to self-efficacy and the sense of autonomy: both dimensions are also integrated during the whole analysis.

II.

As previously explained in the theoretical foundation and Chapter 4 on the Discussion, **previous education** determines the potential for obtaining health literacy. Likewise, higher levels of health literacy, self-efficacy and access to information are the most significant facilitators for informal education (self-directed health education), while also the immediate social environment (peers, friends, family or co-workers), associations and patients'/community's advocates, experts and healthcare professional will play a major role. Socio-cultural inequalities and economic disparities suppose a critical barrier for informal health education, which is very problematic: health literacy is related to knowledge about medicines, self-care and self-management of chronic diseases. Thus, a lack of health literacy may have a negative impact on the acquisition of health behaviours. Moreover, health literacy is one of the most essential factors in decision-making: the sense of autonomy and control that patients obtain through the decision-making and the reaffirmation of the self is a powerful motivator for change, for adopting healthier routines and for increasing, even more, their health literacy and self-care skills.

Implementing health education programmes with individuals in higher vulnerability situations also presents challenges, engaging and retaining the most important ones. The engagement is mediated by social class and, thus, economic circumstances, workload, possibilities and flexibility of the job schedule, credentials, previous education and on-the-job training, but also by the priorities and goals of each participant and their communities and cultures or subcultures, personality and other psychological factors and physical health. Research revised shown that co-production has the potential to foster the sustainability of groups and provide a safe environment, responding to the participants' needs and joining together similar persons able to build long-term relationships and alliances, also generating a sense of identity and community, need for exchanging experiences and knowledge in a secure and trustworthy environment. The engagement, then, appears linked, in-line with the literature, to the communities' empowerment: the potential of health education programmes and mutual support groups for creating and sustaining advocacy and associations, building alliances and cohesive structures should not be ignored.

III.

As previously explained, **well-tailored information** is a powerful motivator for change and for acquiring healthier behaviours. Considering the self-management of health, while the psychological and individuals' factors play a significant role, socio-cultural and socio-economic factors are also involved. Financial hardships, economic difficulties and, again, challenges regarding the workplace and obligations in informal and reproductive work (e.g., informal caregiving) are barriers for self-managing a chronic condition, also mediated by individual factors: self-reflection, self-efficacy, proactiveness, goal-setting skills, or planning skills are important, as well as the social and familiar support and environment.

Health literacy and self-management of the chronic disease influence the decision-making in terms of disposition, willingness, and attitudes by the patient; self-efficacy, again, appears jointly with proactiveness as co-determinants in taking an active role in healthcare. The counselling nature, the patients-providers collaboration, the rapport and the therapeutic relationship are factors to be considered. Age, gender and social exclusion are major forces that may severely impact the patients' disposition to a proactive and participative decision-making.

In terms of self-care and decision-making, an individualistic perspective ignoring the structural, cultural and community's factors will not offer a reliable and rigorous picture; moreover, ignoring the systemic conditions that interfere in the individuals' behaviour may lead to the reproduction of the inequalities and exclusion. Humanisation and the person-centred care should integrate a multidisciplinary, critical and comprehensive understanding of (i) the power differentials in clinical settings and the social field; and (iii) the social, cultural, economic, environmental and structural determinants underlying these disparities.

IV.

Collective empowerment requires autonomous individuals; autonomous individuals need to be acting within a context of collective empowerment: individuals and communities are permanently and continuously interacting. Individuals are not isolated from their historical, cultural and societal realities; communities are composed of heterogeneous individuals and constructed through their historical, cultural and social reflection and self-reflection.

Individually, the autonomy and the real possibilities and potential for autonomy are culturally and socially determined (e.g., by the traditional medical model and the intrinsical power imbalances in the consultation). The expression of the patients' control and the reflection of the patients' autonomy involve the independence, interdependency (e.g., communities, healthcare system/staff), the information available and accessible, the competencies for accessing that information, their skills and self-efficacy for making crucial decisions in the fields of health and self-care and the environmental and social factors, including the structural ones (policies, infrastructures, type of healthcare system, economic crisis or upturns, etc.)

Collectively, communities may encounter genuine challenges and barriers for complying with public health recommendations: lack of resources, problems in accessing health or social services, insurance or fees, poor infrastructures and problems in their members (housing, food insecurity, or job insecurity). It is not a remote and rare circumstance: the conflict between two very distinct realities (the promoters of health communication campaigns and the underserved communities) generate a shock between the lifestyle guidelines and proposals and the real potential, possibilities, and circumstances of deprived and discriminated communities resulting in an alienating and disempowering process, ultimately in confusion, misunderstanding, frustration and mistrust. **Co-production** of guidelines and healthcare innovations, community-based interventions and participative processes, trust-building, and bottom-up approaches are required for supporting communities in their process of empowerment, from a horizontal and non-directive perspective, aware of real-world power differentials between promoters and beneficiaries.

V.

Again, and in-line with the previous point, co-production and co-creation of IT tools and technological innovations is a crucial necessity if the beneficiaries are disenfranchised individuals or groups: the bio-psycho-social context, the cultural, economic and environmental conditions, the access to technologies and the tech divide, the lack of infrastructures that might suppose a lack of connectivity as well, their priorities and most urgent necessities, and their potential reluctances and willingness should be carefully assessed for prioritising those interventions with implementation potential but also those more meaningful and important from the beneficiaries' point of view.

VI.

In sum, the results clearly showed a relation between the access to information and (i) the patient-provider communication; (ii) health literacy (the capacities for self-directing the informal health education, the availability and readiness for engaging in health education programmes, and the ability for applying the acquired knowledge in real settings); and (iii) the decision-making. The access to information and the competencies for selecting, evaluating and applying or using the acquired relates to proactiveness, the capacity for adopting an active role in decision-making and, collaterally, the patients' autonomy. Apart from discrimination and/or stigma, the most important co-determinants of communities' health are the individuals' social class, previous education and their own immediate social environment and social support.

At the collective level, to widen the knowledge of patients is related to the communities' education, literacy and, at last, knowledge as well. The empowerment of these underserved or discriminated communities needs real, actual, and meaningful knowledge, but also identity, bonds, self-appreciation as a community, appropriation of their cultures and worthiness of their particularities. These are foundations for changing policies and accessing key services and resources to reduce even overcoming their health and social disparities.

VII.

These empowerment processes require a paradigm change and a profound understanding of social and structural inequalities: clinical practice is a critical step in promoting the autonomy and the active role of patients, their health literacy, and the access to underserved communities to information, knowledge, bonds and resources. This dissertation proposed the named Critical Clinical Practice, which implies a complete and comprehensive understanding of the power differentials between individuals and groups, awareness of how these are reflected in the counselling and medical intercourses, awareness of their historical, social, cultural and structural basis and the intersectional aspects of oppression, discrimination and stigma; whilst power differentials are not absolutely avoidable, can be reduced or, at least, make explicit to both parties, recognised and self-reflected. Lastly, Critical Clinical Practice requires comprehending how the social, economic and cultural co-determinants are acting in the individuals and collectives health, that these are not a *natural* issue and, consequently, these can be changed.

Research questions and alignment of results with the objectives

This dissertation's **general objective** was to study the paths feasible in clinical settings and within the social fields for unveiling the impact of vulnerability and discrimination, determining how the empowerment can impact communities and individuals' health. All specific objectives are responded too, and contained in, the previous lines: the general objective is,thus,accomplished through the contributions and responses to the specific objectives. In sum, the structural dimension of health inequalities cannot be, and should not be, ignored when analysing these disparities and how these impact individuals' health and public health and their health outcomes, self-management abilities and decision-making competencies.

The Research Question asked about "*the main barriers and facilitators for communicating in health and, specifically, for obtaining information,*

recruiting hard-to-reach populations and facilitating the access to informal education initiatives on health literacy aimed at raising their collective and individual empowerment."

The **most important barrier** is related to the most occurring co-determinants: the social class and all dimensions it involves, the previous education and literacy, and the individuals' social support and environment. At the micro-level, the way in which clinical practice is being conducted may imply to oversee the intersectional aspects of discrimination, the reproduction of inequalities within the social framework and the unawareness of historical and cultural aspects influencing the power differentials within the social hierarchy, stigmatisation and marginalisation.

Then, at the meso-level, communities' disempowerment in the higher situations of vulnerability, deprivation or discrimination supposes a significant barrier in all aspects reflected on the research question, from health communication and access to healthcare to the meaningful participation in health and social care innovation.

Lastly, at macro-level, health policies focused on individuals and individual issues instead of structural and systemic conditions and co-determinants reinforce the disempowerment and alienation of underserved populations and persons. Moreover, basic needs are insufficiently addressed and considered within the Public Health framework and policy reforms. Health policies' reforms can also make a substantial contribution by reinforcing or, on the contrary, changing the traditional medical model and transforming in person-centred care and community-based innovation, which needs to consider the social and structural dimension of the health inequalities.

* * *

Specific research questions asked about how these barriers **(i)** have an effect in the self-management of chronic diseases, (ii) impact on the health information obtained, and (iii) influence its uses and the health outcomes and prognosis; and how (iv) the facilitators for enhancing the self-management of chronic diseases and the acquisition of health information as well as the impact on the individuals' health outcomes. These research questions are responded as line of argument in the paragraphs below, re-interpreted in light of the discussion and the iterative process of analysis.

Firstly, **insufficient access to information**, considering the lack of adapted programmes for health education, suppose a challenge for the self-management of chronicity in highly vulnerable individuals. Additionally, the material circumstances, lack of resources, low access to those public resources if any, job schedules and informal caregiving obligations, financial hardship and problems related to neighbourhoods and infrastructures are critical barriers as well.

Secondly, the barriers and the situation of inequality and discrimination may cause a profound distrust in authorities and, among them, health authorities as representatives of the public administration; some discriminated communities are historically, culturally and socially excluded and marginalised, being their marginalisation reproduced generation by generation and limiting their social mobility .The structural conditions reinforce their distrust and, ultimately, the distrust, translated into disengagement, reproduce their inequalities and disparities at social, economic, or health levels. At the individual level, the insufficient previous knowledge and health literacy/numeracy, lack of support for a complete understanding of the information, the dismissal of their living experience and the low access to knowledge and informal, non-formal, even formal, education. It is due to material and financial problems (e.g., costs attributable to Internet access are not affordable). The autonomous nature of the self-management of chronic health is problematic and misleading if structural circumstances are overlooked.

Thirdly, and linked to the previous education and knowledge acquired, the low health literacy prevents to obtain meaningful learning or, at least, a rapid adaptation to the occurring disease and the implementation of efficient self-management and coping strategies. Besides, there might be insufficient abilities and competencies for translating the received information into knowledge, then, for translating into a deep understanding of the information able to be transferred to practical actions and applications in real-life settings. However, these barriers are modifiable: they are not *natural*, are not *essential* and *immutable* barriers, are not constitutional factors of individuals isolated from their own social context. These barriers are socially and structurally determined and can be overcome and changed whilst difficult due to its normalisation.

Recapturing the general objective of this dissertation, the understanding of health inequalities and their structural, socially determined nature, and the ways in which it can be overcome reveals the necessity of a profound transformation that should be aligned and paired with policies able to put the persons and the communities in the centre. It is needed to support the generation of participative structures able to support the empowerment processes, to foster the patients' autonomy and to reinforce the social awareness of professionals and institutions for critically analysing how the social, cultural, economic and environmental co-determinants of health and the structure of the social field itself is interwoven in their clinical practice.

Strengths and limitations

Whilst strengths are considered an important added value of the present dissertation, some shortcomings are identified.

Firstly, it should be noticed and recognised that the quality of the sampled studies is heterogeneous; although the criteria for including studies were robustly founded on the research questions and objectives, and different quality control mechanisms were put in place, different types of studies coexist together; the central topics vary, as well as the conceptual richness and the contribution to the research field. Concerning the quality control mechanism, only papers rated as very good and excellent following the CASP for qualitative primary studies were included, attending to their clarity, relevance and richness, and carefully considering the high-quality and peer-reviewed grey literature (specifically, PhD and MsC dissertations included).

Secondly, the variable contribution to the research field, the heterogeneous extension or format and the vast sample included supposed an additional difficulty in analysing the information and, moreover, in generating lines-of-arguments and in theory-building. Albeit, this limitation was overcome through an innovative approach for an enormous meta-synthesis.

Thirdly, and linked to the present research's conceptual richness, it should be recognised that, due to the scope and formal limitations, poor attention was paid to particular problem areas and specific sub-groups and communities. As it will be further explained in Future research lines, gender aspects, specific issues concerning minorities and particular discrimination and oppression settings would need more detail and analysis by themselves. Correspondingly, this PhD dissertation focuses on highly prevalent chronic diseases limited the analysis, vision and perspective of the already invisible rare diseases. The analysis of structural dimensions and social co-determinants of health in rare diseases, their living experience and the self-management and communication challenges encountered by patients seem to be a promising research area that should be further explored. The decision of focusing on chronicity and highly prevalent diseases responded to the necessity to urgently tackle the social, historical, cultural, and structural problem areas underlying the health disparities and, so, the discrimination and stigma for a vast percentage of the population. Besides, the high prevalence and burden on persons, communities, and society raised the question about the potential that person-centred care, self-management, and empowerment of underserved communities have to reinforce and preserve the public health system.

As already emphasised, this dissertation covered a vast sample: 103 studies were included and analysed. This atypical situation is both, a weakness and a strength of the research: it is a weakness because of the research challenges that it supposed and the methodological difficulties encountered for constructing lines-of-argument, middle-range theories and, most importantly, the generation of recommendations for practice, which is one of the key aims and objectives of the present work. It is a strength, also: the tremendous amount of literature revised allowed a comprehensive overview of the structural mechanisms, individuals' and communities' factors co-determining health, engagement and empowerment and, even, the researchers' and providers' assumptions, beliefs and positions, transmitted throughout the studies revised.

The innovative methodology consisted of merging the Meta-Synthesis model with the Grounded Theory; the innovation permitted to analyse the discourse of key persons involved in the research as a whole, providing a robust framework of analysis and a reliable organisation of the information, as well as a future direction for conducting vast qualitative meta-studies. This innovation allowed us to obtain and, most important, to clearly organise and re-interpret in an iterative way a vast range of information about the participants' perspectives, solutions proposed, assumptions, beliefs, strengths, and structural problems in their own terms, which is crucial for constructing well-founded lines-of-argument but very difficult and challenging given the size of the sample. In sum, this innovative methodological approach allowed authors not to lose important information, facilitating the extraction and iterative re-interpretation of key thematic areas, allowing themes and codes arise from the information and avoiding attaching to a single framework that might be counterproductive in terms of conceptual richness but still preserving the clarity and the conceptual organisation, comparison and results delivering.

The integrative perspective and the focus on the individuals' autonomy and the community empowerment for focusing the engagement is a meaningful strength of our study that must be considered joined to the transparency, honesty and clarity of the research and theoretical foundations and researcher's expectations. The theoretical position was stated early in the introduction, ensuring that potential bias and assumptions are explicitly stated and, thus, maintaining the rigour and the robustness of the analysis and the contributions.

Last, but no less important, the present research has important implications for real-world practice in clinical, research and community settings; these are already reflected and summarised in Chapter 5 on Recommendations and implications for practice and are aimed at practitioners, professionals, researchers or patients and communities' advocates. The translation of research into practice is the most essential strength and added value of this research work and the critical contribution to the field, able to support, at least partially, the policy change required to strengthening and empowering persons and collectives and, ultimately, the society as a whole.

Future research lines

As it has been already introduced, the analysis of specific realities is the most important shortcoming of the present research: future research lines should consider widening the perspective and complete the present work by analysing these questions applied to different age groups and, specifically, youngsters and seniors; while the research in older citizens is increasing, there is a lack of systematic evidence for analysing the structural mechanisms involved in health communication, engagement and empowerment in youngsters, whose might encounter additional challenges in autonomy, decision-making and self-management considering their position in the social hierarchy and their potential lack of independence.

Also, specific attention from a gender point of view is required, in particular, in regards the queerness and masculinities. Currently, the research on women's health and femininities is, fortunately, a growing research field, focusing on living experience and structural and social co-determinants of health, engagement, and empowerment would be a promising and interesting research for LGBTIQ+ folks and for males. Other intersectional questions around the bodies and the embodiments should be integrated within that analysis being critical in researching the gender aspects of counselling with males (binary or not) and queer folks.

Rare diseases and the challenges that having a rare condition entails are another thought-provoking research line: rare diseases present additional difficulties in communication and validation/dismissal in the medical consultation, access to reliable information, patients' alliances and collective empowerment, decision-making, autonomy and self-management of health and, lastly, the patients' living experience.

While extensive research on peer-based health literacy and mutual support groups for highly marginalised and stigmatised groups (e.g., homeless, sex workers, etc.) is been and has been conducted, it is also needed to translate their findings into summaries of best practices, success cases, recommendations and guidelines for public health advocates, professionals, practitioners and, above all, associations and leaderships liaising with these particular and hard-to-reach groups.

Lastly, specific and empirical research of IT, mHealth and online health literacy groups and programmes for deprived and impoverished communities is needed: there is not clear how these tools can be applied in real settings when the connectivity and the affordability of devices are not guaranteed, and there is a lack of evidence on their own priorities and considerations about IT tools in general terms; preliminary, it seems that co-production and co-creation of these type of solutions are required, but also that these innovations cannot substitute the previous and appropriate meeting of their basic needs: housing, education, access to healthcare and regular income. Besides, their preferences and customs, ways of interaction and use of technologies and interfaces should be analysed by a comprehensive, qualitative, and critical perspective; thus, community-based participatory research frameworks may be appropriate.

* * *

In sum, this dissertation encountered key mechanisms, problem areas, challenges, enhancers, and barriers related to healthcare access, communication and counselling, autonomy, patient access to information, self-management of chronic conditions, and decision-making health literacy and education and communities' empowerment.

Apart from individuals' characteristics, relationships, and the organisations' particularities and the subaltern, counterhegemonic and normative/hegemonic communities, covert, non-obvious structural mechanisms underly the health and social inequalities.

These disparities should be unveiled and addressed from a socio-political approach, directly stressing and addressing the macro settings and promoting a profoundly transformation and change of paradigm in the relationships within the social field, the care system, and public policies overcoming the inequality health gap. Without recognising its broad, deep, complex and structural nature, all public health efforts targeted to the individuals are at risk of being trivial, banal, insignificant and meaningless.

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