

Priorities for health and care research

Findings from an analysis of research priorities
agreed by UK service users, carers and professionals
(James Lind Alliance Priority Setting Partnerships)



This tool has been designed for UK-based researchers and research funders in health, biomedical and social sciences.

It may also be useful for members of the public, clinicians, care professionals and others.

See [Background](#) for more information about this tool, including examples of how it can be used. Or start exploring priority [Topics](#).

For researchers

- › See which topics have been repeatedly prioritised across multiple areas of health and care by [James Lind Alliance](#) Priority Setting Partnerships in the UK
- › Strengthen your research proposals by addressing topics of known importance to a wide range of service users, carers and professionals
- › Help choose or refine your research questions
- › Consider who you could collaborate with (from which areas of health and care)

For research funders

- › See which topics have been repeatedly prioritised across multiple areas of health and care by [James Lind Alliance](#) Priority Setting Partnerships in the UK
- › Help ensure your funding calls and funding decisions are informed by the priorities of service users, carers and professionals
- › Explore topics of particular interest to your organisation

What are James Lind Alliance (JLA) Priority Setting Partnerships?

The [James Lind Alliance \(JLA\)](#) is a non-profit making initiative which brings together service users, carers and professionals in [Priority Setting Partnerships](#). These partnerships each focus on a particular area of health or care, working to agree on the [Top 10 priorities](#) which most urgently need addressing by research. They follow a rigorous process to identify, verify and prioritise unanswered questions, described in the [JLA Guidebook](#).

Why was this tool developed?

To stimulate new research and foster collaboration, the [NIHR Oxford Biomedical Research Centre](#) funded a research project to identify overarching topics among Top 10 priorities. These topics are ‘overarching’ because they have appeared in 3 or more JLA Priority Setting Partnerships across different health categories within the [UKCRC Health Research Classification System](#).

Using a technique called thematic analysis, the project team analysed 515 Top 10 priorities from 51 UK-based JLA Priority Setting Partnerships completed between January 2016 and December 2020. They identified 89 overarching topics, grouped under [7 umbrella topics](#). This tool helps people navigate the overarching topics and underlying research priorities. For examples of how researchers and research funders might use this tool, [click](#) here.

Please note that if a topic of interest does not appear in this tool, it could still exist among JLA priorities. The analysis was based on a 5-year sample of priorities and was influenced by the unique perspectives of those involved.


Who did the research?

The project was led by a senior researcher at the University of Oxford, in collaboration with an international group of service users, carers, clinicians, researchers, research funders and public involvement specialists (named [here](#)). For more information, see our [project report](#).

How might people use this tool?


Example 1

To inform a future funding call, a research funder with a remit to improve health services wants to see which overarching topics are relevant and what proportion of PSPs have prioritised each one

- › They look at the umbrella topics on page 5 and click on Services and systems which takes them to a new page showing 8 overarching topics relating to services and systems.
- › They click on the 'open' icon  in the 'Services and systems' circle to view a table of underlying data. This shows the proportion of priorities, PSPs and health categories underpinning each overarching topic in the study sample. The most frequently prioritised topic is 'Optimising multi-agency & multi-professional coordination' (27% of PSPs and 29% of health categories).


Example 2

A social scientist wants to see if there are any overarching topics that could inspire their next research proposal

- › They look at the umbrella topics on page 5 and click on Social influences and impacts which takes them to a new page showing 7 overarching topics relating to social influences and impacts.
- › They are drawn to the 'Addressing health inequalities' topic as this is of particular interest to them. They click on the 'open' icon  next to it.
- › This takes them to a table listing the 8 priorities, 7 PSPs and 4 health categories underpinning this topic in the study sample. The list gives them an idea of the sorts of questions which have been asked, and the areas of health and care which might be good places to look for collaborators.


Example 3

A public contributor has been asked to get involved in a research programme to improve shared decision making between patients and professionals. Before agreeing, they want to know if this topic is important to patients and carers across a wide range of different conditions

- › They search (using Ctrl+F) for the keyword 'decision' and find the overarching topic 'Enabling and improving shared decision making' on page 10.
- › They click on the 'open' icon  to view the underlying information, and see that 8 (16%) PSPs covering 6 (29%) health categories in the study sample highlighted this topic among their Top 10 priorities. This indicates it is important to patients and carers across a wide range of different conditions.



Click on circles to view overarching topics or scroll to view each one in turn

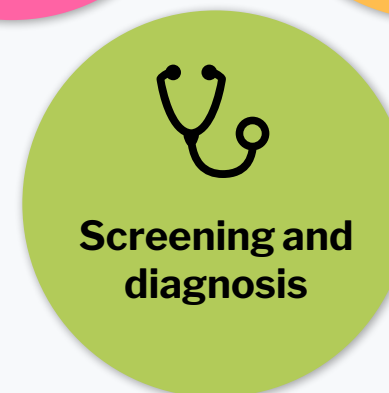
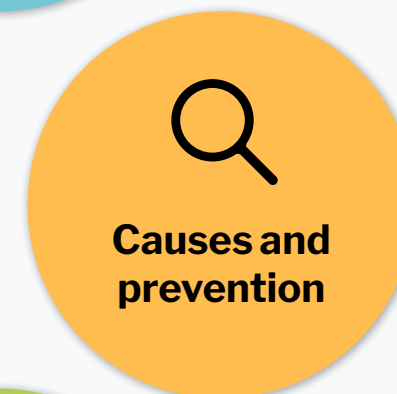
Click 'open' icons  to view downloadable priorities, PSPs and health categories underpinning overarching topics

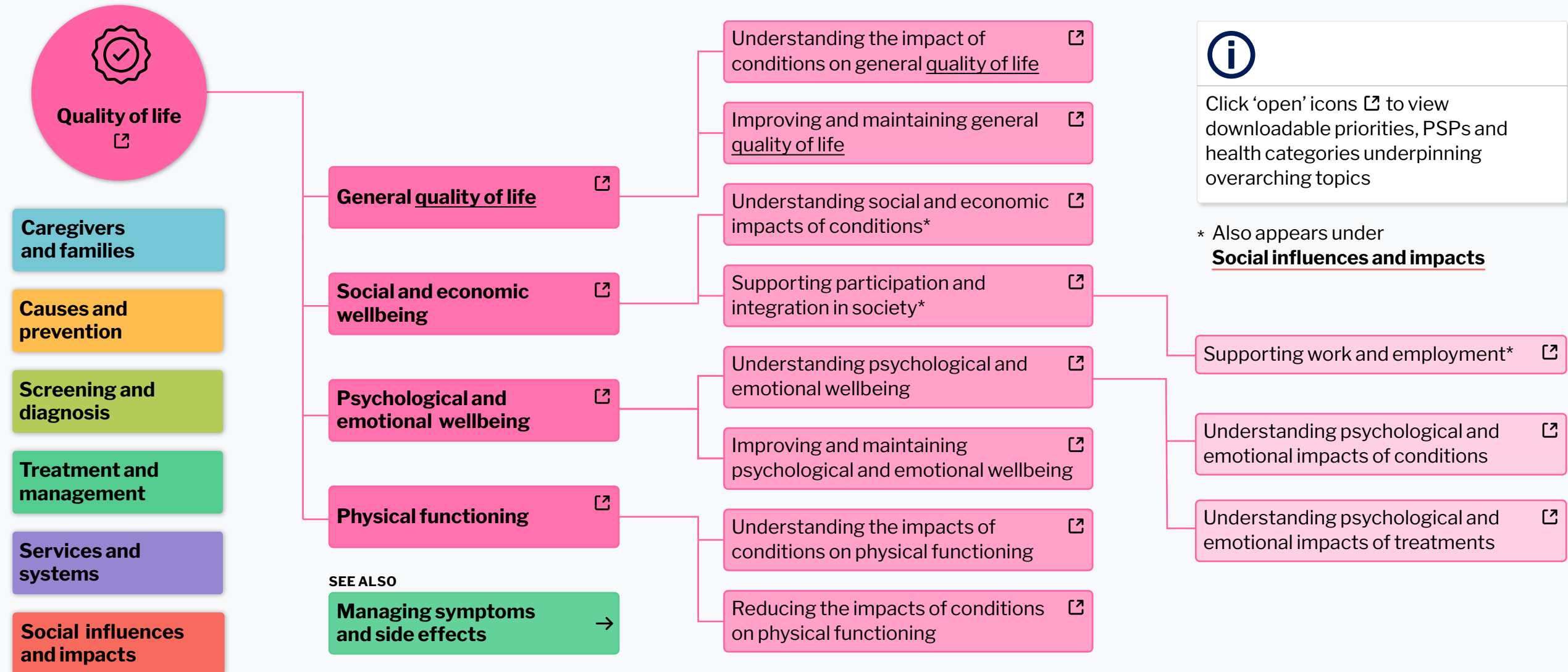
Click top banner to return to this page

Click underlined words for glossary descriptions

Press Ctrl + F to search for a keyword

If you would like to view all the priorities within a certain **health category** in the study sample (rather than within an overarching topic), please see our separate [table of priorities](#) and filter by health category in the corresponding columns.





Quality of life



Empowering caregivers
and families

Understanding the
influence of family*

Supporting the wellbeing
of caregivers and families

Understanding the impact
on caregivers and families

Improving professional
engagement and
communication with
caregivers and families


SEE ALSO

Quality of life →

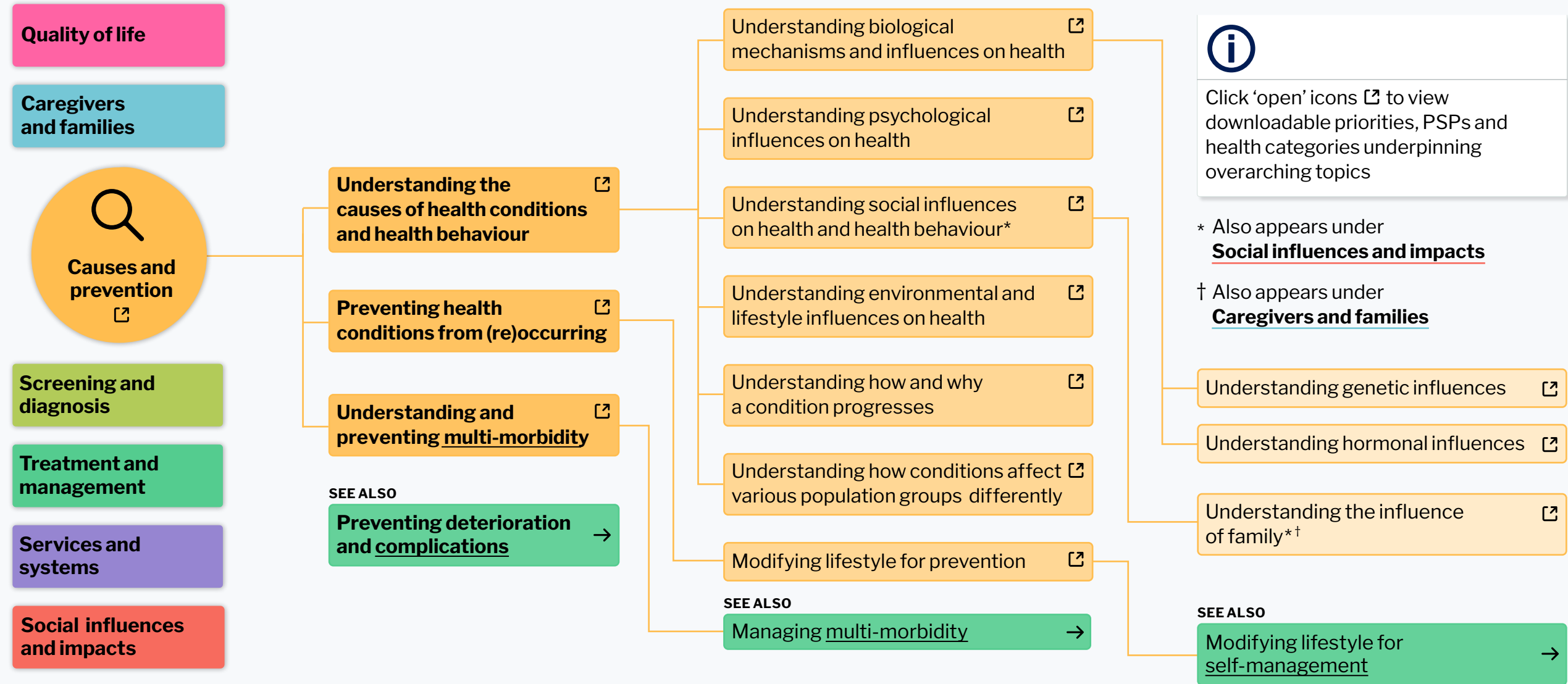
SEE ALSO

Improving communication
and information sharing →



Click 'open' icons  to view
downloadable priorities, PSPs and
health categories underpinning
overarching topics

* Also appears under
Social influences and impacts
and **Causes and prevention**



Quality of life

Caregivers
and families

Causes and
prevention



Treatment and
management

Services and
systems

Social influences
and impacts

Reducing time
to diagnosis



Finding the best test,
tool or method for
screening and diagnosis



Non-invasive techniques
(unspecified)




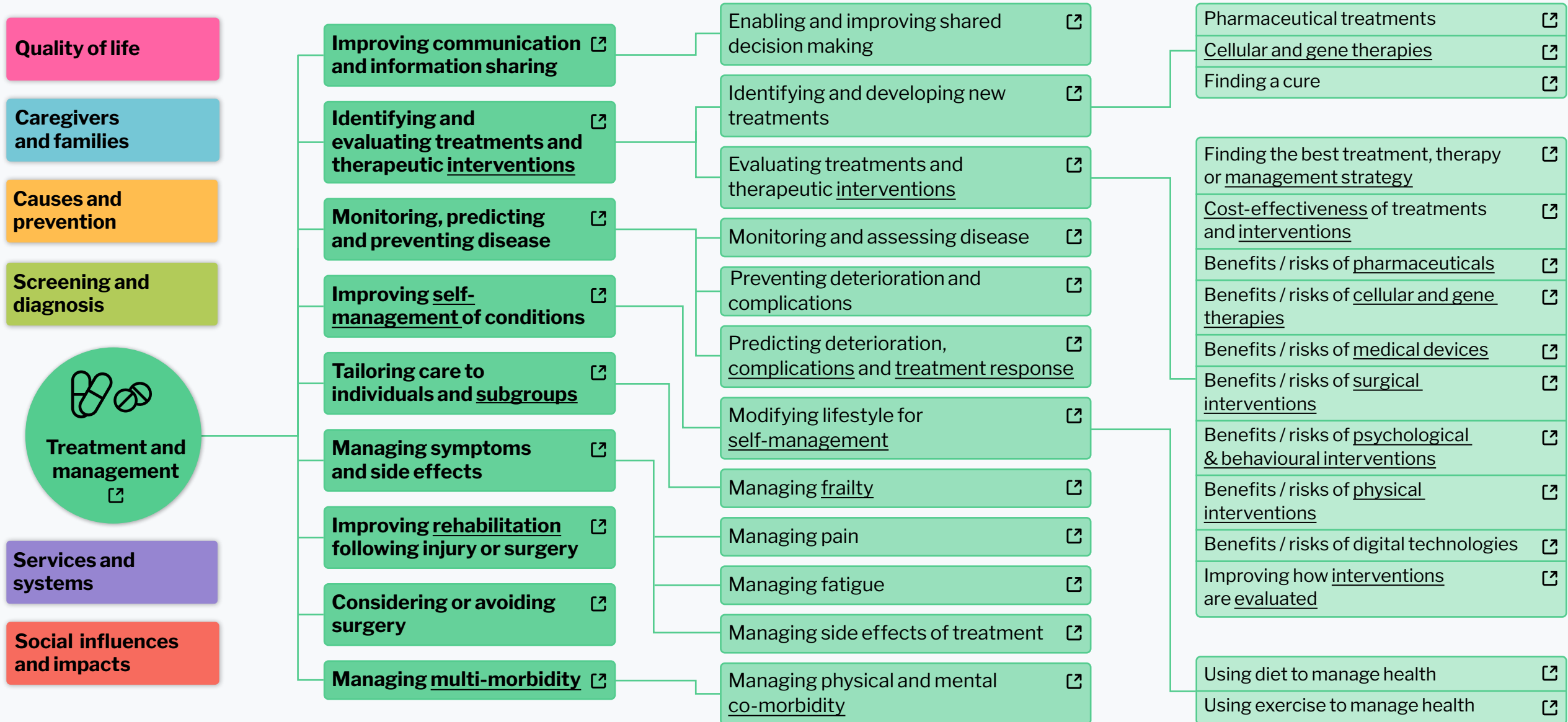
Imaging techniques




Blood tests

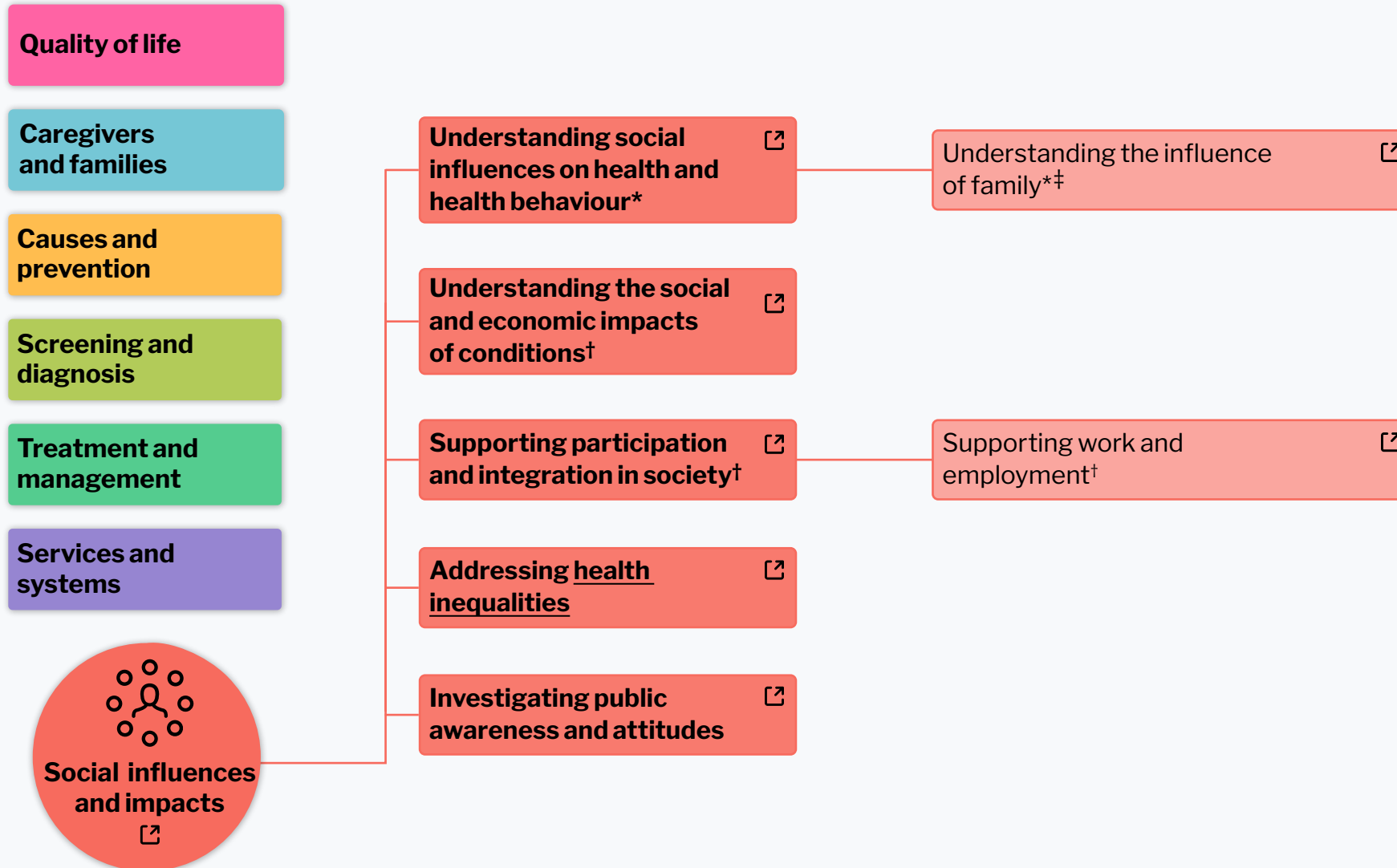



Click 'open' icons  to view
downloadable priorities, PSPs and
health categories underpinning
overarching topics





Click 'open' icons  to view downloadable priorities, PSPs and health categories underpinning overarching topics



Click 'open' icons  to view downloadable priorities, PSPs and health categories underpinning overarching topics

* Also appears under **Causes and prevention**

† Also appears under **Quality of life**

‡ Also appears under **Caregivers and families**

Caregivers – people who regularly look after someone with lived experience of a health condition, whether formal/paid workers or informal/unpaid family members or volunteers.

Cellular and gene therapies – treatments that involve transferring intact, live cells or genetic material (DNA) into a patient’s system to help lessen or cure a disease. For more information see the [American Society of Gene and Cell Therapy](#).

Co-morbidity – health condition that occurs at the same time or directly after another health condition. They are often chronic (long-term) such as diabetes and high blood pressure.

Complication – additional medical problem that makes an existing condition more dangerous or difficult to treat.

Cost-effectiveness – extent to which something is cost-effective i.e. provides good value or benefit for the amount paid.

Evaluate – to formally judge or calculate the quality, importance or value of something e.g. a particular treatment.

Frailty – condition of being physically weak and not in good health. In medicine, frailty defines the group of older people who are at highest risk of adverse outcomes such as falls, disability, admission to hospital, or the need for long-term care. (from [NHS England](#))

Health inequalities – avoidable, unfair and systematic differences in health between different groups of people. The term is also used to refer to differences in the care that people receive and the opportunities that they have to lead healthy lives – both of which can contribute to their health. For more information see the [King’s Fund](#).

Imaging techniques – ways of seeing inside the human body, often used to diagnose a condition. Examples include X-rays, ultrasound scans, MRI scans and CT scans.

Intervention – something that aims to make a change and is tested through research. For example, giving a drug, providing a counselling service, improving the environment or giving people information and training are all described as interventions. (from [Cambridge Biomedical Research Centre](#))

JLA or James Lind Alliance – a non-profit initiative set up in 2004 to enable those grappling with health issues on the ground – patients, carers and clinicians – to decide together what health research questions most urgently need answering. See [JLA website](#).

Management strategy – overall approach or combination of treatments used by a care professional to manage a person’s condition.

Medical devices – medical devices include implantable devices, mobility aids, dressings, medical equipment and prostheses used in healthcare.

Multi-morbidity – presence of two or more long-term health conditions in a person. For more information see the [National Institute for Health and Care Excellence \(NICE\)](#).

Non-invasive techniques – medical tests or procedures which do not cut the skin or enter the body.

Overarching topic – topic which has appeared in Top 10 priorities from 3 or more JLA *Priority Setting Partnerships* across different areas of health and care.

Palliative care – approach which aims to improve the quality of life and quality of death of people with a terminal illness by offering physical, emotional and practical support to them and their families.

Pharmaceuticals – drugs used in healthcare. They include small molecules, vaccines, antibodies and hormones.

Physical interventions – these include physical therapies, physiotherapy, occupational therapy, speech therapy, dietetics, osteopathy and exercise used to treat or prevent health conditions.

Priority Setting Partnership (PSP) – a collaboration of service users, carers and professionals working to identify and prioritise unanswered questions in a particular area of health or care. They follow a systematic process developed by the [James Lind Alliance \(JLA\)](#).

Professional – someone who formally treats or cares for people with a health or health-related condition, e.g. clinicians, nurses and other allied health professionals, psychologists, social workers and educators.

Psychological & behavioural interventions – these include therapies or programmes aiming to improve psychological wellbeing or change behaviour, including social interventions.

Quality of life – person's general wellbeing or the degree to which they are healthy, comfortable and able to enjoy the activities of daily living. It includes physical, psychological, social and environmental aspects.

Rehabilitation – programmes or treatments aimed at restoring health or reducing disability.

Screening – way of finding out if members of the public have a higher chance of having a health problem, so that early treatment can be offered or information given to help them make informed decisions (from [NHS website](#)).

Self-management – approaches which aim to empower people with long-term conditions to take control of their treatment and care. For more information see the [Patients Association](#).

Subgroups – in our tool this means people with certain demographic characteristics (e.g. a specific age or gender) or clinical characteristics (e.g. people with cardiovascular disease or frailty).

Surgical interventions – treatments that involve surgery.

Treatment response – effect a treatment has on a person's health condition.

Umbrella topic – one of 7 large overarching topics containing smaller overarching topics within it (see [page 5](#)).

For more information about contributors to the project, please see our [project report](#)

Project funded by

[National Institute for Health and Care Research \(NIHR\)](#)
[Oxford Biomedical Research Centre](#) and University of
Oxford [Returning Carers' Fund](#)

Project lead

[Joanna Crocker](#) (Interdisciplinary Research in Health
Sciences (IRIHS), Nuffield Department of Primary Care
Health Sciences, University of Oxford)

Collaborators

Tootie Bueser, Sally Crowe, Toto Gronlund,
Maaz Khan, [Lucy Moore](#), Margaret Ogden, [Noémi Roy](#),
Casper Schoemaker, [Madeline Tatum](#), Mark Taylor

Advisers

[Gunilla Åhrén](#), [Ben Davies](#), [Teresa Finlay](#), [Kristina Staley](#),
Sanjay Thakrar, Ayath Ullah

Service user and carer participants

Jennifer Bostock, Corina Cheeks, Hameed Khan,
Lynn Laidlaw, John Laville, Manoj Mistry, Shirley
Widdop, Max Williamson, Laurence Woollard and
one person who preferred to remain anonymous

Many thanks also to

The James Lind Alliance Coordinating Team
(Beccy Maeso and Caroline Whiting), [Joseph Wherton](#)
and [Trish Greenhalgh](#) for their guidance and support

PDF created by

[Design Science](#)
with photos from [Pexels.com](#)

Please cite this tool as

Crocker J., et al. 'Priority topics for health and care
research: Findings from an analysis of research
priorities agreed by UK service users, carers and
professionals (James Lind Alliance Priority Setting
Partnerships)', 2022. Available from: phc.ox.ac.uk