Priorities for Health and Care Research

An analysis and synthesis of information from James Lind Alliance Priority Setting Partnerships

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About this project

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About the authors

Joanna Crocker was project lead and is a Senior Researcher at the University of Oxford's Interdisciplinary Research in Health Sciences Group, Nuffield Department of Primary Care Health Sciences. She has a background in health sciences and research methods, including a Masters in Biochemistry from the University of Oxford, a PhD in Public Health and Primary Care from Cardiff University, and postdoctoral mixed methods research at University College London. She is experienced in quantitative and qualitative health research methods and has a long-standing interest in patient and stakeholder involvement in health research, including research prioritisation. Her interest in the James Lind Alliance began with a co-produced evaluation of an early Priority Setting Partnership in 2015.[1]

Margaret Ogden is a patient and public involvement partner from County Durham, UK. Her involvement work spans health, public health and social care. She has broad experience of JLA PSPs including providing patient and carer perspectives at three PSP final workshops. As well as being a valued team member throughout this project, she has also assisted a Masters student with her dissertation on JLA research priorities. More recently, she is one of three Patient and Public Involvement representatives on a JLA PSP with St Georges Hospital on Outpatients.

Lucy Moore is a Health Service Researcher at the University of Oxford's Interdisciplinary Research in Health Sciences Group, Nuffield Department of Primary Care Health Sciences. She has a Masters in Advanced Health Care Practice from Oxford Brookes University and a PhD in Medical Studies from the University of Exeter, Peninsula School of Medicine and Dentistry. She has worked clinically in the UK and USA, and as a postdoctoral researcher in Canada at the University of Alberta, Edmonton. Her interests include the management of health and illness and how technologies can support healthcare delivery and inequalities of access. She has experience in patient and public involvement and the use of quantitative and qualitative methods, specialising in medical sociology and ethnography. Lucy has supported all three parts of this project, in particular mapping information sources and coding and categorising research priorities.

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[1] Snow R, Crocker J, Crowe S. Missed opportunities for impact in patient and carer involvement: a mixed methods case study of research priority setting. Research Involvement and Engagement. 2015;1:7.

Contents

Thanks

We are very grateful to the following colleagues for invaluable contributions to coding the data in Part 2 of the project and/or acting as second reviewers to help identify overarching themes in Part 3 of the project:

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- **Casper Schoemaker**, Carer & Juvenile Idiopathic Arthritis PSP Co-Lead, University Medical Center Utrecht, Netherlands
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- **Mark Taylor**, Head of Strategic Partnerships, Central Commissioning Facility, National Institute for Health and Care Research, UK

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- **Casper Schoemaker**, Carer & Juvenile Idiopathic Arthritis PSP Co-Lead, University Medical Center Utrecht, Netherlands
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Executive summary

Introduction

James Lind Alliance (JLA) priority setting partnerships (PSPs) produce Top 10 lists of research priorities in a particular area of health or care, decided together by people with lived experience of the area in question, their carers and families, and professionals who provide care. In this way, PSPs help researchers and funders to understand what the key beneficiaries of their research - people with lived and professional experience - think is most important. PSPs have reported a range of positive impacts of their work and Top 10 priorities, including a shift in research funding towards the issues that matter most to people with lived experience, carers and care professionals.

To date, over 130 PSPs in different areas of health and care have published Top 10 research priorities. PSPs naturally promote their Top 10 priorities to researchers and funders with a particular interest in their topic. However, some PSPs may share similar priorities, which could potentially be combined, promoted and addressed in collaborative ways. Likewise researchers and funders with non-condition specific remits may be interested in common priorities emerging across PSPs. Our project aimed to facilitate new research and research funding by:

(1) describing the nature of information published by PSPs on, or signposted from, the JLA website;
(2) describing the characteristics of Top 10 research priorities produced by JLA PSPs;
(3) identifying overarching topics and themes common to Top 10 research priorities from UK-based PSPs in different areas of health and care.

In order to address these aims, we carried out three distinct activities whose methods and findings are summarised below.

(1) Mapping PSP information

We created an inventory of information published on (or signposted from) the JLA website for each PSP. We described the content, location, format and availability of each information source.

All 101 completed PSPs in our sample had published their Top 10 priorities, and most had published:

- their protocol (this was 100% for more recent PSPs);
- a data management spreadsheet (usually in PDF format);
- the Top 20-30 priorities ranked at the final workshop;
- a journal article.

Despite their frequent absence, the following information sources may be particularly helpful for people using PSP priorities. We encourage all future PSPs to publish them on the JLA website:

- For each Top 20-30 priority, an explanatory note in lay language, and examples of original uncertainties submitted by service users, carers and professionals.
- A final project report summarising the whole PSP process and providing further information about each Top 10 priority (in addition to the above).

- A Data Management Spreadsheet in locked Excel format, including original submissions and clearly labelled “out of scope” and “already answered” questions. The latter two are not currently required of PSPs, but some do provide them.

(2) Characterising Top-Ten Research Priorities

We coded 636 Top 10 research priorities, published by 63 PSPs between 2016 and 2020, by

- Health Category and Research Activity from the UK Health Research Classification System (HRCS)
- COMET outcome domain
- Demographic sub-population (age, gender, ethnicity)

Most (81%) came from the United Kingdom, while the remainder came from Canada (11%) and other countries internationally. The priorities covered a wide range of HRCS health categories, most commonly “Generic Health Relevance” (meaning applicable to all disease and conditions or to the or to the general health and well-being of individuals – 23%), “Mental Health” (18%) and “Musculoskeletal” (14%). They also spanned the full range of HRCS research activities, from basic underpinning research and aetiology (causes of health conditions) to applied research into health and care services. The most common research activities were management of diseases and conditions (43%), evaluation of treatments and therapeutic interventions (32%) and health and social care services research (19%). Nearly one third of priorities were concerned with specific demographic subpopulations, mostly relating to age and/or gender.

The distribution of UK-specific PSP priorities across the HRCS starkly contrasted the distribution of UK direct health research expenditure across the same categories during an equivalent time period, with some of the most frequent health categories and research activities receiving relatively little funding. This suggests that PSPs are focussing on areas of unmet need.

(3) Identifying overarching themes

We analysed a subset of 515 Top 10 research priorities from 51 UK-based PSPs, in collaboration with service users (including patients and carers) and clinicians, to identify overarching themes – that is, themes which encompass priorities from three or more PSPs covering two or more health categories or “Generic Health Relevance” (from the HRCS). We identified 89 overarching themes and sub-themes, which we grouped under seven topics:

- Quality of life
- Caregivers and families
- Causes and prevention
- Screening and diagnosis
- Treatment and management
- Services and systems
- Social influences and impacts

We developed an interactive PDF tool to help researchers, funders and service users to navigate these overarching themes. The tool can be accessed by clicking here.

Recommendations for users of PSP priorities

For researchers, funders and others wishing to address or otherwise use PSP priorities, we recommend using all the available information about each priority to understand it as fully as possible. This may include the explanatory note and examples of original uncertainties associated with PSP priorities on the JLA website where this is available, the PSP final report, and/or the Data Management Spreadsheet. PSP leads can also be contacted for further information about particular priorities via the JLA Coordinating Team. For anyone wishing to code PSP priorities using the HRCS, please refer to our guidance (see Appendix C) and if helpful, our coding for PSP priorities published between 2016 and 2020.

1. Introduction

Typically, researchers decide what research questions to answer and funding organisations decide what research to fund. However, these decisions may differ from the views of those grappling with health issues on the ground – service users and carers with lived experience, and the professionals who treat them.[2] The James Lind Alliance (JLA) is a non-profit initiative set up in 2004 to enable patients, carers and clinicians to decide together what health research questions most urgently need answering. This is often different from what researchers and funders think needs addressing. The JLA process begins with the formation of a priority setting partnership (PSP) focusing on a particular health condition or caring profession. The JLA facilitates the PSP, and the PSP itself is responsible for the funding and organisation. Funds may come from one main organisation or charity or smaller contributions may be made by several partners in the PSP, but PSPs cannot be directly funded by a commercial organisation that could benefit commercially from the results. Many times PSPs are instigated by a research organisation to direct the research it plans, or by a funding organisation to inform its funding strategy.

Service users (including patients and carers), care professionals and other stakeholders with relevant experience are invited to submit questions they would like answering, usually via an online “harvesting survey”. These then go through a thorough process of filtering, grouping and interim prioritisation described in detail in the JLA Guidebook[3]. The process ends with a workshop in which the top 20-30 prioritised questions are discussed and ranked by service users, carers and care professionals, guided by an expert facilitator, to produce an agreed “Top 10” list of research priorities. The PSP then promotes these to researchers and external funders, with the aim of changing the research agenda to better reflect the interests and concerns of those with lived experience as a service user or carer, and those who treat them. PSPs have reported a range of positive impacts of their work and Top 10 priorities, including a shift in research funding towards the issues that matter most to service users, carers and care professionals, changes in organisational culture, and benefits for the individuals involved.[4]

To date, over 130 PSPs have published Top 10 lists of research priorities, covering a very wide range of health conditions and caring professions, and now include PSPs beyond the health and social care sector (for example, adult social work and learning difficulties). The scope of PSPs has broadened, from focusing only on “treatment uncertainties” in the earlier years of the JLA, to now identifying and prioritising “evidence uncertainties”, the scope of which is determined by the PSP. Although most PSPs have been based in the UK, an increasing number of PSPs from other countries have published research priorities.

With the large number of PSPs now in existence, there comes the opportunity to bring together the information they produce to answer broad questions about research prioritisation and priorities. PSPs naturally promote their Top 10 priorities to researchers and funders with a particular interest in their topic. However, some PSPs may share similar priorities, which could potentially be combined, promoted and addressed in collaborative

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[2] Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Patients’, clinicians’ and the research communities’ priorities for treatment research: there is an important mismatch. Research Involvement and Engagement. 2015;1:2. https://doi.org/10.1186/s40900-015-0003-x

[3] The JLA Guidebook can be viewed online here: https://www.jla.nihr.ac.uk/jla-guidebook/

[4] See “More Than a Top 10” report by Kristina Staley and Sally Crowe: https://www.jla.nihr.ac.uk/making-a-difference/downloads/More-Than-a-Top-10-report.pdf

ways. Likewise researchers and funders with non-condition specific remits may be interested in common priorities emerging across PSPs, but may not have the resources to identify these themselves. Our project aimed to make use of this rich resource to inform future PSPs, research and funding decisions beyond specific conditions or care specialties.

1.1 Rationale and scope

The Advisory Group helped to determine the scope of the project during its first meeting in December 2020. In response to the question "What would project success look like?", the group brainstormed several potential indicators of success. Following the meeting, advisory group members took part in a ranking exercise by email to reduce the list to a manageable number. The final three project aims were designed to reflect the top three most highly ranked indicators of success overall, which were:

(i) an overview of published data from JLA PSPs, accessible to researchers, service users, lay members of the public and other stakeholders;
(ii) overarching themes which cut across PSP priorities, some translated into new funding calls and/or research projects;
(iii) a description of the characteristics of PSP priorities (e.g. research activity types, health/other areas).

We agreed that ideally, we would include the Top 20-30 research priorities debated at PSP final workshops in the above goals; however for practical reasons we would limit the analysis to Top 10 research priorities. The identification of overarching themes was limited to UK-based PSPs, because we felt that the contextual similarities of UK-based PSPs would better enable identification of themes meaningful to UK-based health research funders. However, the overview of published data and description of priority characteristics was not restricted by PSP host country.

1.2 Project aims

From the top three indicators of success identified by the Advisory Group, we established three aims for the project:

(i) to describe the nature of information published by PSPs on, or signposted from, the JLA website (including content, format, location and availability);
(ii) to describe the characteristics of Top 10 research priorities produced by JLA PSPs, in terms of health category, type of research activity required, outcomes and demographic sub-population (if specified);
(iii) to identify overarching themes common to Top 10 research priorities from PSPs in different areas of health and care.

These aims were intended to build on each other. Aim (ii) requires using some of the information identified to address aim (i), while aim (iii) builds on the analysis required to address aim (ii).

1.3 Who worked on this project and how it was funded

The project was developed and led by Joanna Crocker at the Nuffield Department of Primary Care Health Sciences, University of Oxford, with support from a number of colleagues and guidance from an Advisory Group (see Section 1.3). The project idea came from conversations she had with the JLA Coordinating Team, Sally Crowe and other stakeholders interested in bringing together information and outputs from across PSPs. The work was funded primarily by a grant given by the National Institute for Health and Care Research (NIHR) Oxford Biomedical Research Centre (BRC), at the direction of Prof Trish Greenhalgh, Director of the Partnerships for Health, Wealth and Innovation theme of the Oxford BRC in 2017-2022. Additional funding for research assistance was awarded by the University of Oxford Returning Carers' Fund in 2021.

The project was independent of the James Lind Alliance (JLA) Coordinating Team based at the National Institute for Health and Care Research, who did not fund or steer the direction of the project. The extent of their involvement was to provide helpful information to aid project design and understanding of the information published on the JLA website. Toto Gronlund, an independent JLA Adviser, was a member of the project Advisory Group and provided advice and guidance throughout the project, as well as helping to identify overarching themes in Part 3 of the project.

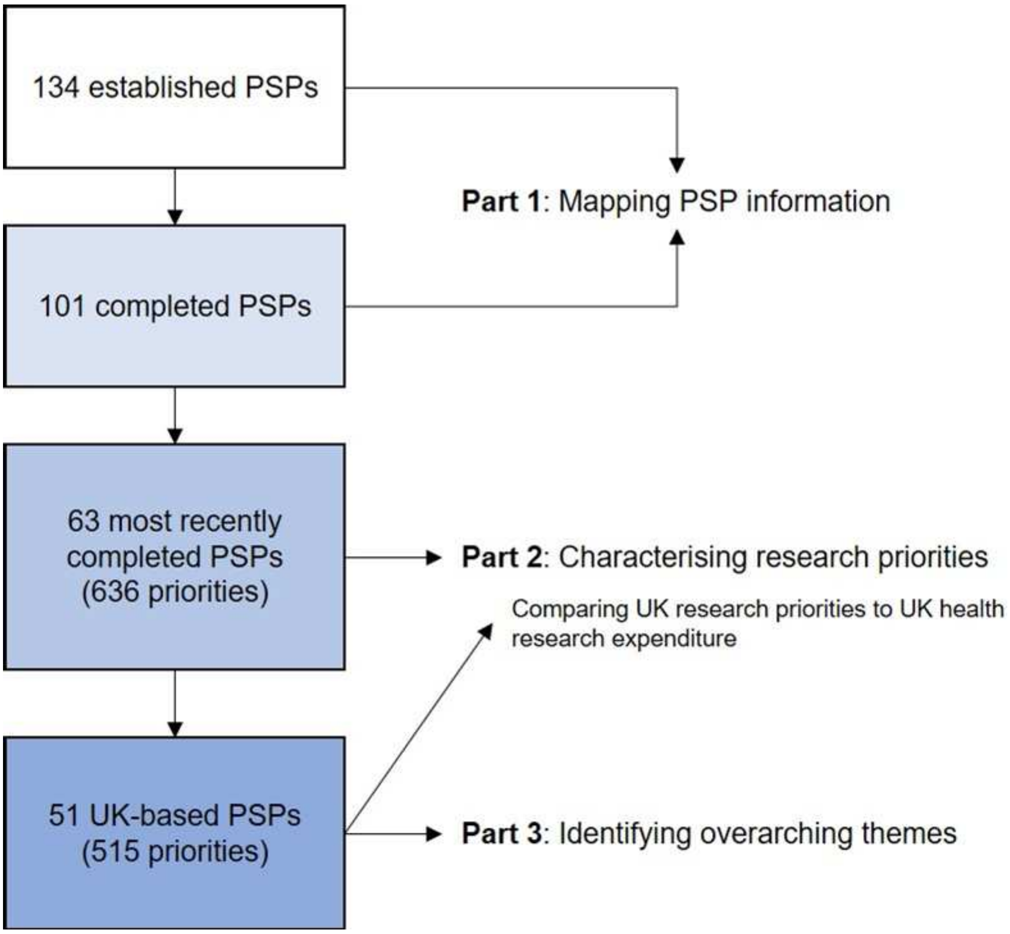
1.4 Overview and approach

This project was a collaboration between people from a diverse range of stakeholder groups and perspectives including service users, carers, clinicians, PSP leads, patient and public involvement specialists and health research funders. An Advisory Group, made up of 13 members from all of these groups in the UK and internationally, was established by the project lead in Autumn 2020 and strongly influenced the direction, aims, design and findings of the project. They met three times during the project (December 2020, May 2021 and February 2022) and also gave regular input via email correspondence and one-to-one or small group video calls. The project was also informed by one-off conversations with other stakeholders including funders and research support staff (e.g. regional NIHR Research Design Services).

In this project we used qualitative and quantitative methods, with input from the multi-disciplinary Advisory Group, to generate new knowledge which we hope will lead to action (for example, new research addressing overarching priorities).

The project comprised three distinct parts, corresponding to the three aims of the project. Each part involved analysing a subset of PSPs from the previous part, as summarised in Figure 1 below.

Figure 1: Project components



1.5 Terms used

The key terms used in this report are defined as follows:

- **Priority Setting Partnership (PSP)** - A collaboration aiming to bring together people with lived experience, caregivers and professionals to jointly identify priorities for research in a particular area of health, following the method set out in the JLA Guidebook and facilitated by one of a small team of JLA Advisers.
- **PSP priorities** – The Top 10 list of research priority topics produced by PSPs.
- **Health Research Classification System (HRCS)** – A framework developed by the UK Clinical Research Collaboration (UKCRC) Partners to enable UK health research funders to classify and strategically assess the research they have funded. It classifies research by Health Category and Research Activity.
- **Overarching theme** – A theme which encompasses PSP priorities from three or more PSPs, collectively covering two or more HRCS Health Categories or "Generic Health Relevance".
- **COMET** - The COMET Initiative brings together people interested in the development and application of agreed standardised sets of outcomes, known as 'core outcome

sets'. These sets represent the minimum that should be measured and reported in all clinical trials of a specific condition, but core outcome sets are also suitable for use in routine care, clinical audit and research other than randomised trials. You can read the core outcome set/COMET plain language summary here.

- **Service user** - Someone who has lived experience of the condition, problem or service in question (including patients).
- **Carer** or **Caregiver** – Someone who regularly looks after a person with lived experience of a condition, whether formal/paid or informal/unpaid.
- **Professional** – Someone with professional experience of the condition or problem in question (including health, social care and other professionals).
- **PSP Lead** – The person with overall responsibility for the PSP, who works closely with the JLA Adviser and PSP Coordinator.

1.6 Structure of this report

The remainder of this report is divided into three sections, corresponding to the three different parts of the project:

- **Part One:** Mapping the information published by PSPs. This section describes the methods we used to create an inventory of the information published by PSPs on, or signposted from, the JLA website. It describes the findings and their implications for future PSPs and researchers interested in using PSPs' research priorities.
- **Part Two:** Characterising Top-Ten research priorities. This section describes how we coded 636 research priorities by health category, research activity, outcome domain and demographic sub-population. It describes the findings and their implications.
- **Part Three:** Identifying overarching themes. This section describes how we identified overarching themes from a subset of 515 research priorities, and presents 82 overarching themes grouped into seven broad topics. It also describes how we developed an interactive PDF tool to help users navigate these themes, and provides a link to the tool.

Following these three sections, we summarise our recommendations for researchers, funders, service users and future PSPs, and discuss strengths and limitations of the project, before stating our final conclusions.

2. Part One: Mapping the information published by PSPs

This part of the project was considered necessary in order to understand what information PSPs publish on the JLA website, how often this is available (since there is great variability in what PSPs publish) and its qualities. This could help stimulate new research ideas and proposals using the available information. It would also help us to understand what information might be available to support Parts Two and Three of the project.

2.1 Methods

The aim of this part of the project was to describe the nature of information published by PSPs on or signposted from the JLA website. We included all documents and information sources reporting PSP methods, characteristics and/or outcomes. The full list with descriptions can be found in Appendix B and included the following:

- Information about the PSP: country, funder, date Top 10 research priorities were published.
- Mandatory documents (required by JLA): protocol, steering group terms of reference, engagement summary, data management spreadsheet, question verification form.
- Other (non-mandatory) information e.g. harvesting survey, interim survey, project report, Top 20-30 research priorities discussed at final workshop, extra information associated with Top 10 research priorities, promotional materials, journal articles, evidence of funded research and evidence of further work on Top 10 priorities.

For each of these information sources, a researcher (LM), working closely with the project lead (JC), recorded its presence or absence for all PSPs completed in or before December 2020. We also recorded information about its content, format and location on the JLA website.

For each information source, we worked out the proportion of PSPs for which it was available on or signposted from the JLA website. We also split PSPs into three roughly equally weighted time periods (based on date of Top 10 publication) – 2007-15, 2016-18 and 2019-20 – and compared the availability of information sources across these time periods.

2.2 Findings

In total, we mapped information sources for 134 PSPs, of which 101 (75%) had completed i.e. published its Top 10 list of priorities at the time of analysis. An Excel spreadsheet showing the presence/absence of each information source for each PSP (up to and including December 2020) can be viewed here.

Figures 2 and 3 show the proportion of completed PSPs for which each information source was available on or signposted from the JLA website. Funders, researchers and other organisations interested in using Top 10 lists may be interested in PSP *outputs* (Figure 3), while new JLA PSPs and methodologists may be interested in PSP *process* information (Figure 2). Process information is the documentation that shows or qualifies the steps a given PSP took to create a Top 10 list.

Some of the process information sources, particularly the protocol (which became a publication requirement towards the end of 2018), showed a clear trend for increasing availability over time, i.e. more recent PSPs were more likely to have published it (Figure 4).

By contrast, journal articles and other publications showed the opposite trend, reflecting the time lag between PSP completion and external publication of outputs.

Figure 2: Process information published by completed PSPs (N=101)

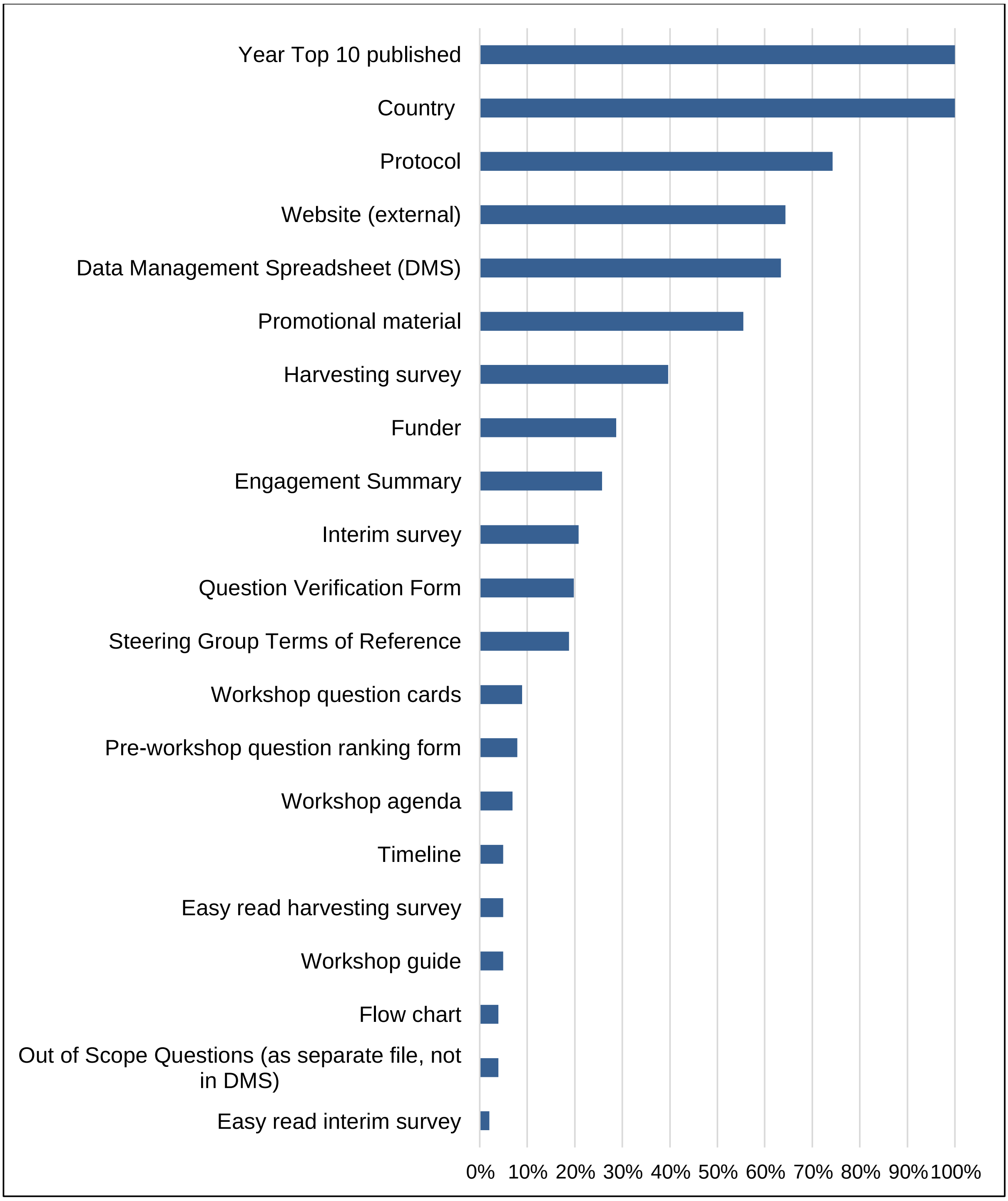


Figure 3: Outputs published by completed PSPs (N=101)

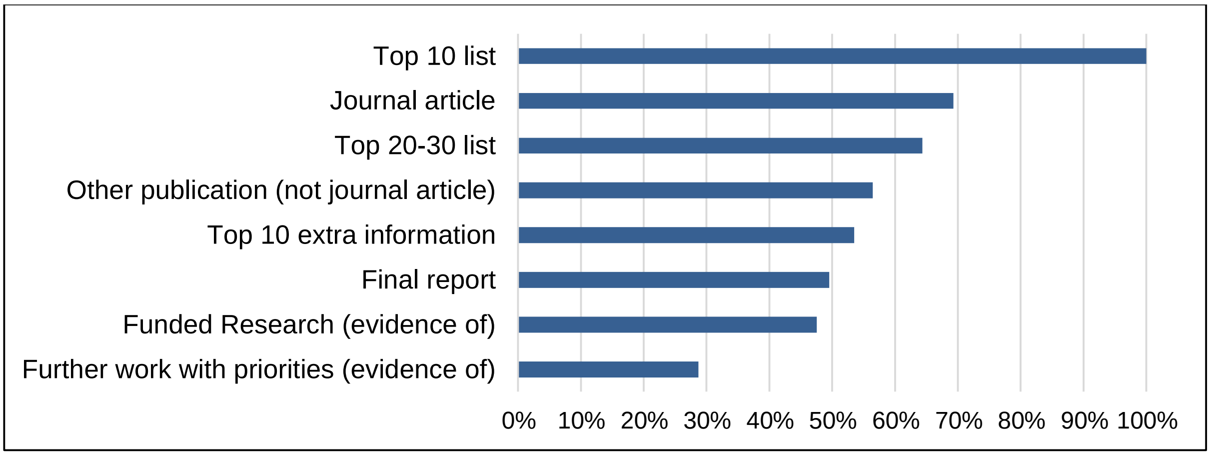
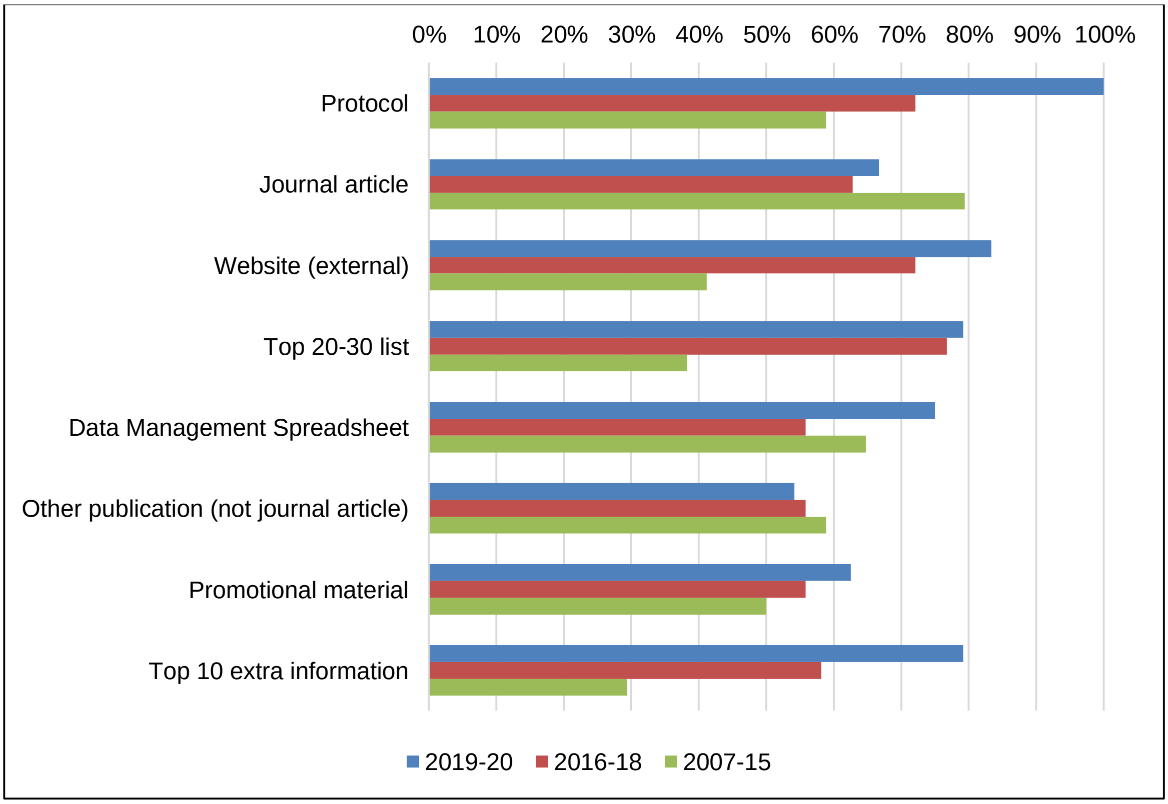


Figure 4: Information availability by time period (for >50% availability overall) (N=101)



The only information published by *all* PSPs were the host country and Top 10 list of priorities. Other information sources were missing for some PSPs to a greater or lesser extent (though the protocol had been published by all those completing in 2019 or later).

Based on our observations and use of PSP information for Parts 2 and 3 of the project, there were three information sources that were often insufficient. We would urge future PSPs to consider developing these documents as they would be particularly helpful for people wishing to address PSP priorities or otherwise use them for research:

- **Explanatory notes and examples of original uncertainties** – for older PSPs, these sometimes appear in a table hyperlinked to the corresponding Top 10 priority on the JLA website; for more recent PSPs, these are sometimes included in the Data Management Spreadsheet. Explanatory notes in particular were very helpful in understanding and interpreting the research priority, although they were rarely available. The Occupational Therapy PSP provided exemplary explanatory notes. For example, priority 4 "What are the long-term benefits of occupational therapy intervention?" was accompanied by this explanation: "This question asks about the enduring impact of occupational therapy interventions after intervention has finished. Does the person who accessed occupational therapy services continue to benefit from the intervention/s once they've been discharged from occupational therapy? What is the nature of any lasting benefits? How do they compare to the benefits measured at discharge?"
- **Data Management Spreadsheets** have the potential to be rich datasets for future research, as well as demonstrating the process through which Top 10 priorities have come. We found that most Data Management Spreadsheets were in PDF format, included questions which were considered in scope and unanswered, but did not include all original submissions. A small number of PSPs, for example Endometriosis and Acne[5], provided a separate table of all responses received from the harvesting survey. Most helpful would be spreadsheets in locked Excel format, including clearly labelled out of scope questions, already answered questions, and original submissions.
- **Project reports** often gave a very useful summary of the whole PSP process, or the final workshop, and the resulting Top 10 research priorities. Most helpful were reports which gave further contextual and explanatory information about each priority. For example, the Autism and Epilepsy (Canada) PSPs gave a full page of the report to each Top 10 priority.

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[5] The Acne PSP survey response data are not available on the JLA website but were published in an open data repository.

3. Part Two: Characterising Top 10 research priorities

3.1 Methods

To describe the characteristics of research priorities, we coded each priority by:

- Health Category within the Health Research Classification System
- Research Activity within the Health Research Classification System
- COMET taxonomy of outcomes
- Demographic subpopulation (age, gender, ethnicity or other)

We also considered coding by academic discipline using the Joint Academic Coding System, but decided against this due to the large number of codes and multiple potentially relevant disciplines per research priority. Similarly, we considered distinguishing between quantitative and qualitative research activities, but agreed that since most research priorities could be addressed using both quantitative and qualitative methods, this would not have been a helpful distinction.

Four members of the team contributed to the coding:

- A mixed-methods health researcher with a non-clinical background in biomedical and health sciences (also the project lead, JC)
- A patient and public involvement specialist with experience facilitating JLA PSPs and with a background in nursing (SC)
- A health services researcher with a background in nursing (LM)
- A fifth-year UK medical student (MK)

Initially, each priority was double-coded – that is, coded by two members of the team (the project lead and one other) independently (meaning they were blind to the other person's coding). They used the HRCS Handbook and online guidance to help determine which HRCS codes to use. Initially, these pairs of coders then met to compare codes, discuss the discrepancies and agree final codes. Usually this was sufficient, but in rare cases of doubt or inability to come to an agreement through discussion, a third member of the team reviewed the priority and gave an opinion about the coding; the majority opinion was then taken as the final code. This initial period of coding was very time-intensive due to the high level of disagreement between pairs of codes and therefore frequent need for discussion between coders. We found that the levels of disagreement between pairs of codes declined over time, but remained relatively high, particularly in relation to HRCS Research Activity and COMET outcomes. The latter was especially difficult because in many cases, clinical outcomes were implied but not explicit or not specified, leading to a significant degree of judgement by coders. HRCS Research Activity also required a judgement regarding the nature of research needed to address a particular priority, sometimes with no information beyond the wording of the priority itself. We therefore made the decision to:

i. Exclude coding of clinical/physiological outcomes. These (where present) aligned with HRCS Health Categories which were already being captured. We continued coding non-clinical/physiological outcomes as these captured a dimension of the priorities distinct from Health Categories, and they tended to be more explicit (for example, "quality of life").

ii. Continue double-coding the entire sample of priorities, but in order to reduce coder discussion time, a third member of the team (project lead, JC) compared the two sets of codes and in the event of disagreement, decided whether to adopt one or both codes. Coders were encouraged to attach explanatory comments to any codes they had doubts about or felt were especially significant, in order to help with these decisions. Occasionally the third team member proposed a different code; this had to be discussed and agreed with at least one of the original two coders before adoption. The final codes were therefore agreed by at least two coders.

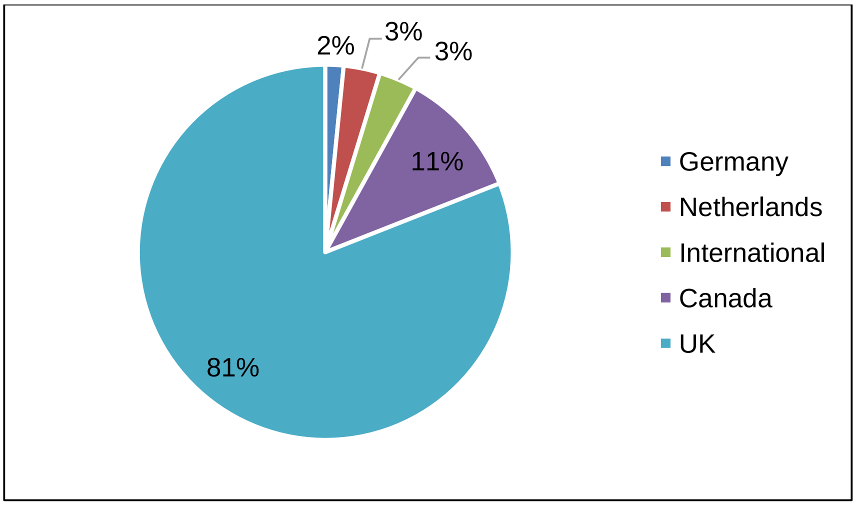
We had initially hoped to code all Top 10 research priorities from all UK-based PSPs; however, this was not possible following the decision to double-code all of them. Instead, we coded the most recently completed PSPs, spanning a 5-year window from January 2016 to December 2020. This constituted 636 Top-10 research priorities from 63 PSPs.[6] We describe our findings in the following section.

3.2 Findings

3.2.1 PSP country

A majority of priorities came from 51 PSPs in the United Kingdom (UK) (81.0%), including 49 UK-wide PSPs, one England-only PSP and one Scotland-only PSP. The remaining priorities came from seven PSPs in Canada (11.0%), two international PSPs (3.3%), two PSPs in the Netherlands (3.1%) and one PSP in Germany (1.6%).

Figure 5: Priorities by PSP country (N=636)



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[6] Although PSPs aim to produce a top 10 list of priorities, there were a few exceptions to this: one PSP (Rare Musculoskeletal Diseases in Adulthood) had two priorities in joint 10th place, one PSP (Liver Glycogen Storage Disease - International) had a top 11 list, one PSP (Scoliosis) had a top 12 list, and one PSP (Early Hip and Knee Osteoarthritis) had three separate top 10 lists relating to different types of priorities. In the latter case, we included only the top four priorities from each list (12 in total) in our analysis.

3.2.2 HRCS health categories

Priorities were distributed across almost all 21 HRCS health categories, as shown in Figure 6 below. The most common health categories were “Generic Health Relevance” (22.6%), “Mental Health” (17.9%), “Musculoskeletal” (13.8%) and Reproductive Health and Childbirth (10.2%). “Generic Health Relevance” includes research applicable to all diseases and conditions or to the general health and well-being of individuals; its high frequency among PSP priorities is largely due to the 14 PSPs in our sample focused on non-disease-specific services or populations. The high frequency of “Mental Health” is due to a combination of PSPs focused on mental health conditions, and priorities (from other PSPs) relating to the psychological wellbeing of service users and carers.

For comparison, Figure 7 shows the distribution by HRCS health category of UK-specific priorities from our sample alongside UK direct health research expenditure in 2018[7] (in descending order of the latter). Stark contrasts can be seen in many categories including Mental Health, Musculoskeletal and Reproductive Health and Childbirth, where the proportion of priorities generated was much higher than the proportion of health research expenditure during approximately the same time period. The reverse trend can be seen for Cancer and Neoplasms and Infection, where the proportion of priorities generated was much lower than the proportion of health research expenditure. These differences suggest that PSPs are focussing on areas of unmet need.

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[7] UK Health Research Analysis 2018 (UK Clinical Research Collaboration, 2020) ISBN 978-0-903730-29-7 https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/

Figure 6: Priorities by Health Category (N=636)

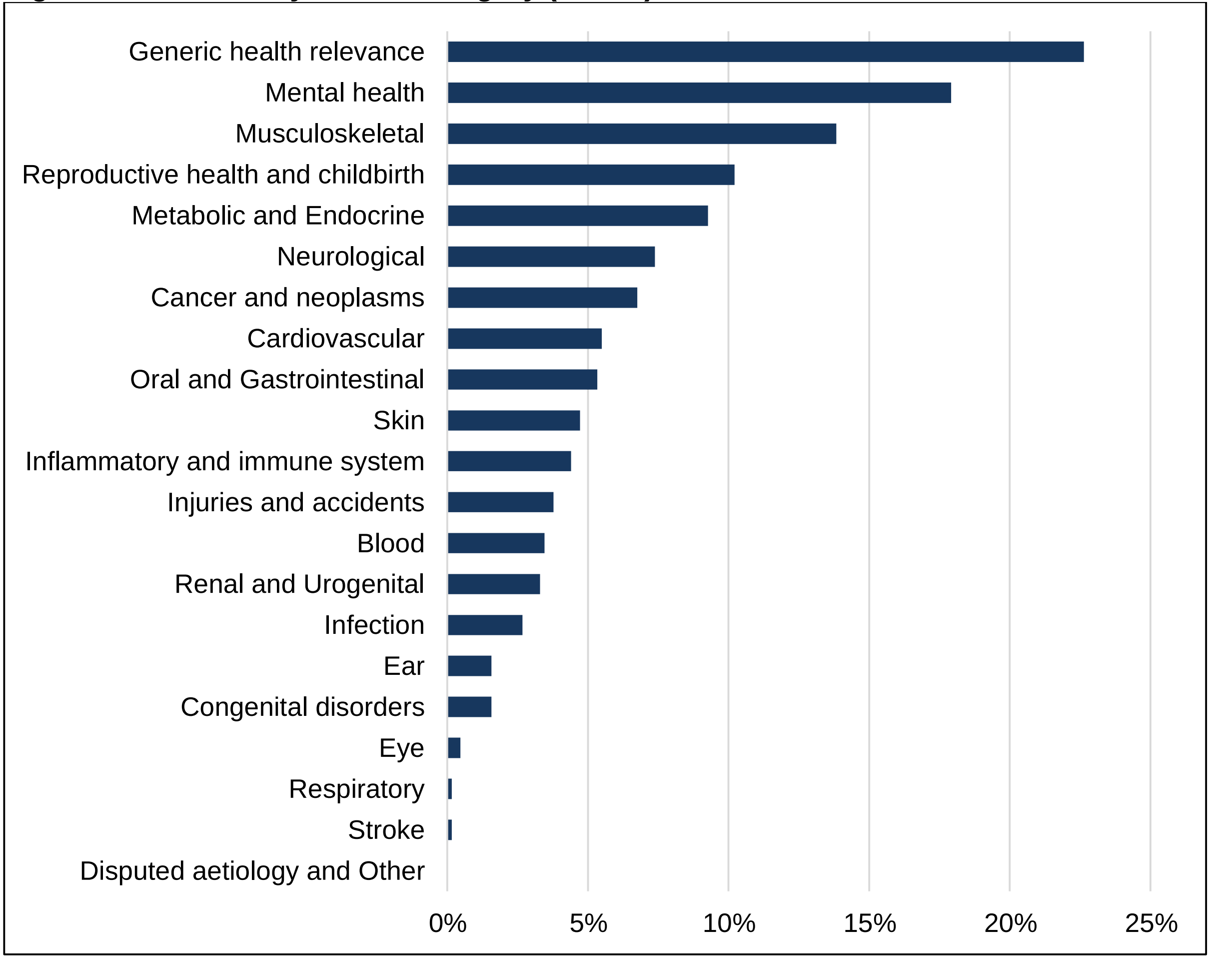
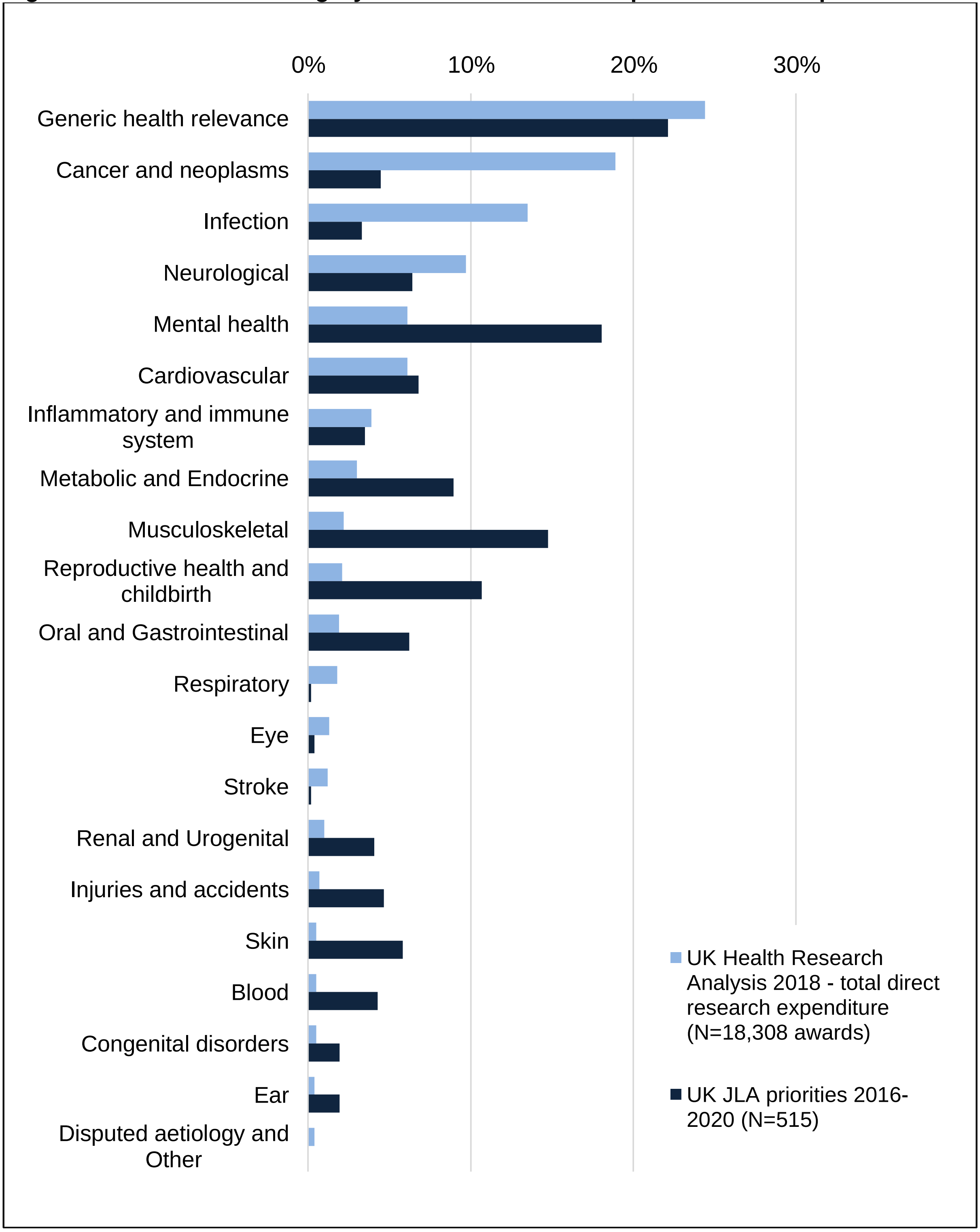


Figure 7: HRCS Health Category: UK health research expenditure vs UK priorities



3.2.3 HRCS research activities

PSP priorities were distributed across all eight HRCS research activity categories as shown in Figure 8 below. The most common research activities were the applied health types: “management of diseases and conditions” (43.4%), “evaluation of treatments and therapeutic interventions” (32.1%) and “health and social care services research” (19.0%). This is perhaps unsurprising, since the service users, carers and professionals taking part in PSPs experience treatment and management in their daily lives.

“Aetiology” (10.1%) and “prevention” (6.0%) were relatively less common among PSP priorities. This could be due partly to some PSPs (especially older ones) excluding disease causation from their scope. Historically, the JLA excluded causation because funding already focused on this; it initially aimed to increase funding in more applied research. Some of the more recent PSPs have also focused on a particular treatment or intervention (e.g. Pessary Use for Prolapse and Digital Technology for Mental Health), so automatically excluding causation. Those PSPs which did include aetiology in their scope often had only one Top 10 priority relating to cause alongside several priorities focused on treatment and management.

Very few PSP priorities (0.8%) were classified as “underpinning research”. This category is used for all types of research into ‘normal’ functions and processes in ‘healthy’ humans or systems, so might seem less relevant to PSPs focused on a particular condition or area of health care.

We assigned “Other” to a small proportion of priorities (2.8%) addressing issues which we could not assign to a specific HRCS research activity. These included priorities concerning settings and sectors beyond health and social care (e.g. schools, workplaces, catering industry) and some priorities relating to public awareness and attitudes.

For comparison, Figure 9 shows the distribution by HRCS research activity of UK-specific priorities from our sample alongside UK direct health research expenditure in 2018.[8] Again, stark contrasts can be seen in most categories including “management of diseases and conditions”, “evaluation of treatments and therapeutic interventions” and “health and social care services research”, where the proportion of priorities generated was much higher than the proportion of health research expenditure during approximately the same time period. The reverse trend can be seen for “underpinning research” and “aetiology”, where the proportion of priorities was much lower than the proportion of health research expenditure. As explained previously, these differences may be due to the historical aims of the JLA and the applied health interests of those involved in PSPs.

For a more detailed breakdown of research activity coding, including subcodes within each category, please see our HRCS coding spreadsheet.

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[8] UK Health Research Analysis 2018 (UK Clinical Research Collaboration, 2020) ISBN 978-0-903730-29-7 https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/

Figure 8: Priorities by HRCS Research Activity (N=636)

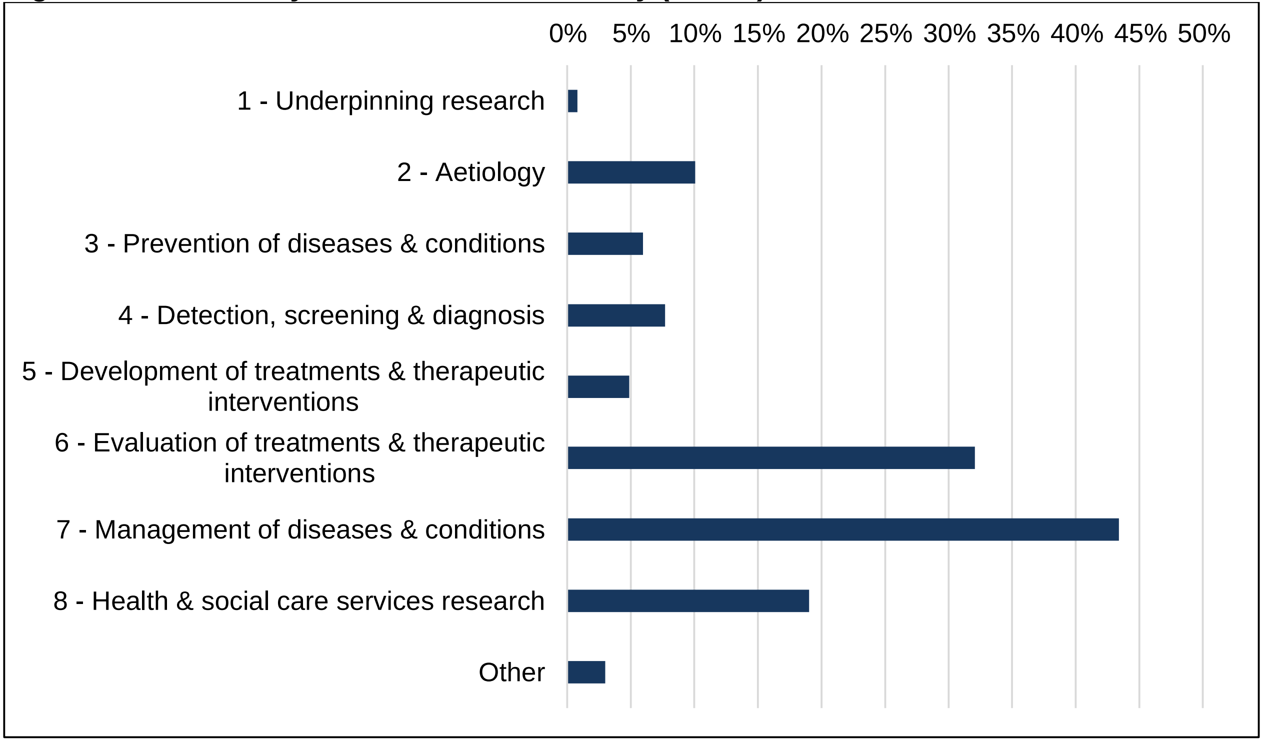
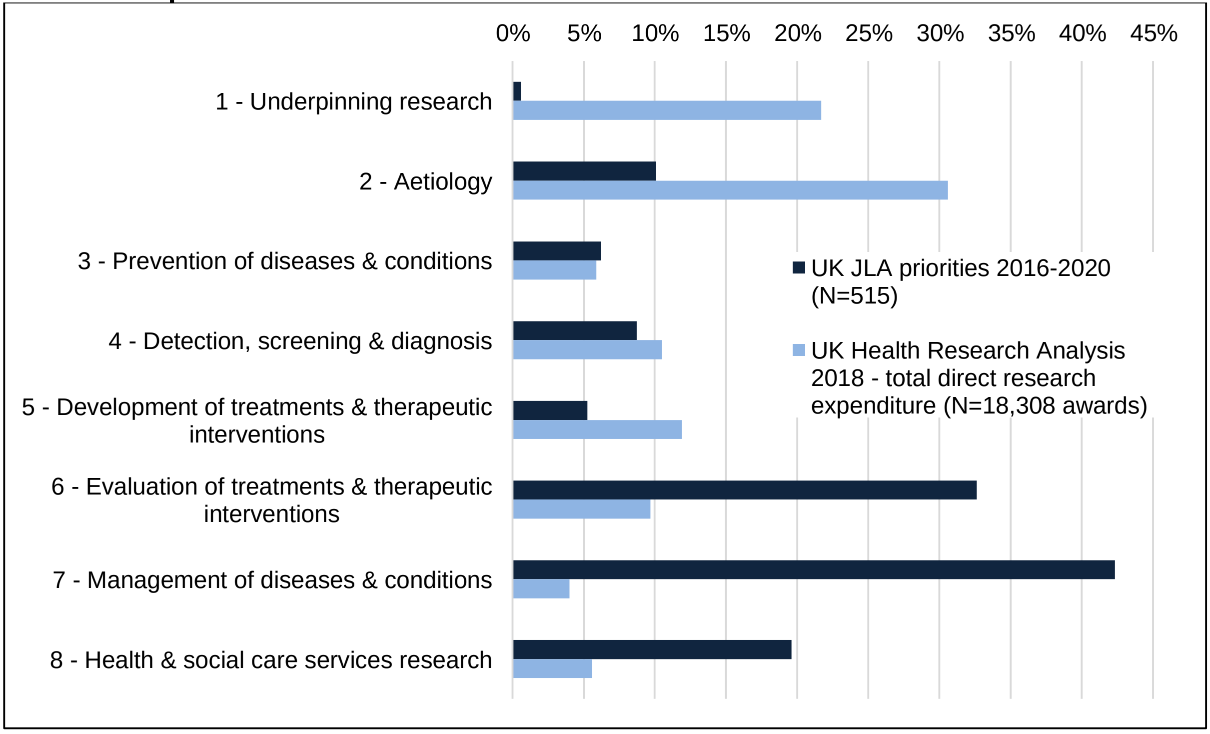


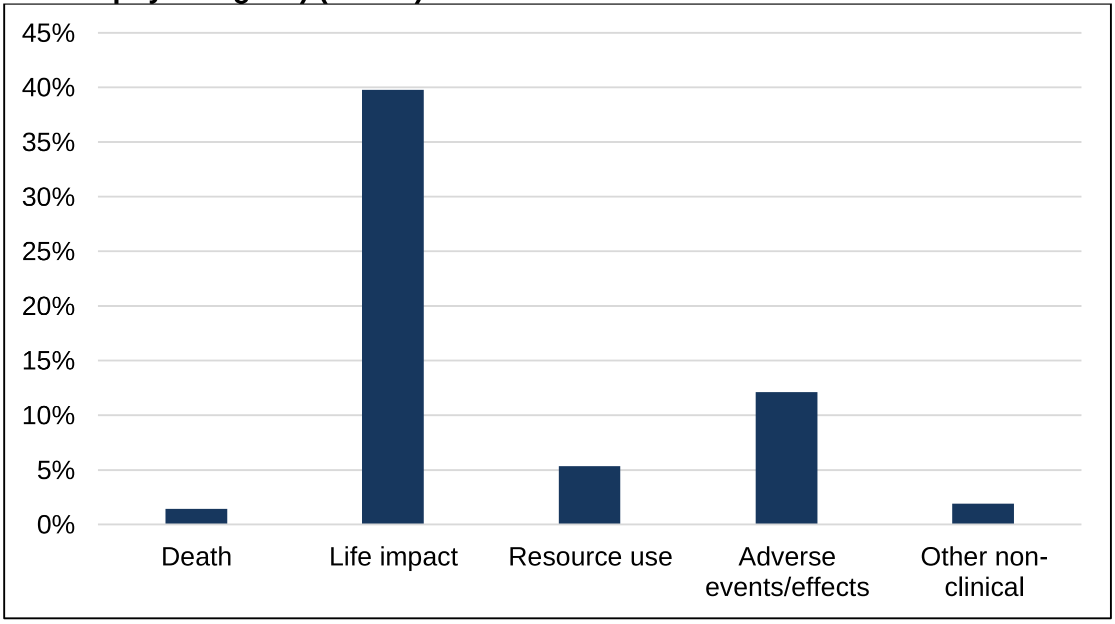
Figure 9: HRCS Research Activity: UK health research priorities vs UK health research expenditure



3.2.4 COMET outcome domains

Just over half of priorities (54.2%) included a non-clinical/physiological outcome, falling into one of the core areas shown in Figure 10 below. “Life impact” was by far the most common of these, associated with 39.8% of priorities. This comprised mainly “delivery of care” outcomes[9], as well as “functioning” outcomes[10] and “global quality of life”. We assigned “Other” to a small proportion of priorities (1.9%) which fell out of the scope of the COMET taxonomy of outcomes. These included outcomes related to health inequalities, societal stigma, behaviour and staff retention.

Figure 10: Priorities by COMET core outcome area (excluding non-clinical/physiological) (N=636)



3.2.5 Demographic subpopulations

Nearly one third (31.9%) of priorities were concerned with specific demographic subpopulations relating to age (20.4%), gender (12.4%), ethnicity (0.5%), or other demographic characteristics (0.6%) including “vulnerable groups”, culture, religion and non-English speakers. Some PSPs themselves were focused on a specific age group or gender, for example “Broken Bones in Older People” and “Blood Pressure in Pregnancy”. In other cases certain priorities within a PSP focused on a demographic subgroup, for example “What would encourage more people (especially black and ethnic minority groups or people with a rare blood type) to donate blood?” (from the “Blood Transfusion and Blood Donation” PSP).

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[9] The “delivery of care” domain of the COMET taxonomy includes outcomes relating to: adherence/compliance; patient preference; tolerability/acceptability of intervention; withdrawal from intervention (e.g. time to treatment failure); appropriateness of intervention; accessibility, quality and adequacy of intervention; patient/carer satisfaction (emotional rather than financial burden); process, implementation and service outcomes (e.g. overall health system performance and the impact of service provision on the users of services).

[10] These include physical functioning (impact of disease/condition on physical activities of daily living), social functioning, role functioning (e.g. ability to care for children, work status), emotional functioning/well-being and cognitive functioning.

4. Part Three: Identifying overarching themes

In this final part of the project, we aimed to identify research priority themes spanning multiple PSPs and areas of care. We refer to these as “overarching themes” and define them as themes which encompass priorities from three or more PSPs covering two or more HRCS Health Categories or “Generic Health Relevance”[11]. For example, the overarching theme “Supporting work and employment” appears in three PSP priorities from three different PSPs (Autism, Depression and Early Hip & Knee Osteoarthritis) which fall under two HRCS Health Categories (Mental Health and Musculoskeletal). Our analysis included 515 Top 10 research priorities from all 51 UK-based PSPs in our Part 2 sample (i.e. published between 2016 and 2020 inclusive). The main purpose of the overarching themes was to highlight cross-cutting areas of importance for potential future research, with funders and researchers (including patient organisations, service user researchers and research organisations) being the primary end users.

4.1 Methods

4.1.1 Workshop with patients, carers and service users

We considered using HRCS and COMET frameworks as a starting point for identifying overarching themes. However, because of their largely clinical academic foundation, we were concerned that they may not adequately capture the perspectives of patients, carers and service users. We therefore invited a group of 11 patients, carers and service users to take part in an online workshop in October 2021 to identify topics meaningful to them. The group was purposely diverse with regard to age, gender, ethnicity and geography within the UK. Almost all of them had experience of one or more JLA PSPs, either as a participant and/or steering group member – we deliberately sought this experience as we felt it was valuable given the focus of the project. Eight people were able to attend the workshop; the three people unable to attend had separate meetings with the project lead to ensure their views could be included. The workshop was professionally facilitated by a member of the advisory group with expertise in public involvement, in collaboration with the project lead (JC) and lay partner (MO). In preparation for the meeting, we asked the workshop participants to view a video presentation explaining the purpose of the project and the workshop, then review and familiarise themselves with 12 randomly-selected research priorities from different PSPs within our sample. Additional information about the JLA and PSPs was provided for those with less experience. During the workshop, we asked participants to work individually and in small breakout groups to find pairs or groups of priorities which were similar in some way that was meaningful to them. We encouraged them to suggest labels or topics for these pairs and groups, as well as topics that were important to them but couldn’t be matched with another priority. We recorded their discussions and noted 30 topics suggested by the workshop participants, as well as 19 topics suggested by the three service users with whom we held separate meetings.

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[11] “Generic health relevance” includes:
- Research applicable to all diseases and conditions or to general health and well-being of individuals.
- Public health research, epidemiology and health services research that is not focused on specific conditions.
- Underpinning biological, psychosocial, economic or methodological studies that are not specific to individual diseases or conditions.

Examples of PSPs coded under this category include “Multiple Conditions in Later Life”, “Emergency Medicine” and “Physiotherapy”.

4.1.2 Conversations with other stakeholders

The project lead (JC) also sought conversations with a variety of interested stakeholders to gather topic ideas. These included the project advisory group, the JLA Coordinating Team, the NIHR London Research Design Service, and national research funders with an interest in non-disease-specific health services, health systems and social science. These conversations resulted in an additional 19 suggested topics for analysis.

4.1.3 Mapping suggested themes against existing coding frameworks

We collated a total of 68 suggested topics from the PPI and stakeholder meetings. We then mapped each suggested topic against HRCS Health Category and Research Activity, COMET framework and sub-population frameworks used in Part 2 of the project. The aim was to identify topics which were not adequately captured by these frameworks, either because they were absent from the frameworks or because they were divided across multiple categories within the frameworks (for example, research about diet can be coded under any one of 6 different Research Activities in HRCS). This mapping was carried out by the project lead (JC) with input from one of our lay partners (MO) and a member of the project advisory group with patient and public involvement expertise, experience facilitating JLA PSPs and a background in nursing (SC). Referring to multiple, previously unfamiliar frameworks was particularly challenging for the lay partner so substantial support was offered. We agreed to remove a small number of topics because they were not relevant to the aims of the project, or were too broad or complex to be useful. About half of the topics were thought to be adequately captured by the existing coding frameworks, while the other half were thought to merit creation of a new code. Some of these new codes were combined because they were very similar. Appendix D lists all of the final new codes created. We refer to these as “stakeholder-generated codes” to distinguish them from the HRCS codes, COMET and subpopulation codes. The project lead applied these new codes to our sample of priorities in three different ways:

- by keyword searching (Appendix D, table 1)
- by combining existing codes from Part 2 (Appendix D, table 2)
- by incorporating them into our inductive analysis of priorities, where they fell within existing codes from Part 2 (Appendix D, table 3)

4.1.4 Inductive analysis to identify overarching themes

By this stage in the project, we had created a large number of datasets for analysis, each dataset containing a list of research priorities assigned a certain code. In order to reduce the number of datasets for practical reasons, we made the decision to exclude the COMET and subpopulation datasets from analysis (with the exception of the COMET Life Impact domain). A large number of priorities did not fit into these two frameworks, because many priorities lack a specified outcome and most do not focus on a demographic subpopulation of service users. By contrast, we had been able to code almost all research priorities by HRCS Research Activity, and there was substantial overlap between HRCS Research Activity and the COMET framework (e.g. priorities coded for “Delivery of care” outcomes tended to have been coded under “Organisation and delivery of services” Research Activity as well). We therefore included only datasets corresponding to HRCS Research Activities, the new stakeholder-generated codes created by keyword searching or by combining existing Research Activity codes, and the COMET Life Impact domain. We included the latter because the PPI workshop highlighted the importance of research on quality of life, but it did not have its own distinct code within the HRCS Research Activity framework.

Many of the datasets overlapped, such that the same research priority could appear in more than one dataset. In order to identify overarching themes, the project lead carried out an inductive thematic analysis on each of these datasets. This is a type of qualitative data analysis in which the researcher closely examines the data to identify common themes – topics, ideas and patterns of meaning that come up repeatedly.[12] In addition to the analysis by the project lead, a "second reviewer" reviewed each dataset independently of the project lead, and proposed their own overarching themes. The second reviewers comprised six members of the project advisory group (CS, MK, MT, NR, TB, TG) and one MSc student from the University of Oxford with a background in public health and expertise in translational health sciences (MT). Following comparison of the two sets of overarching themes, the project lead proposed a revised set of overarching themes; these were presented to the second reviewers and wider project advisory group for feedback, and further revisions were made if necessary.

Part-way through the inductive analysis process, when preliminary analysis of three large Research Activity categories ("Individual care needs", "Management and decision making" and "Organisation and delivery of services") had been completed by the project lead and second reviewers independently, the project advisory group met and worked in small groups to discuss:

- what makes a good or bad overarching theme;
- whether information (such as frequency across PSPs, ranking of priorities) matters;
- what else might be important in interpreting the findings.

Overarching themes proposed by the project lead and second reviewers were used as examples. Second reviewers did not work on their own suggested themes, and suggested themes were presented without revealing the identity of the person who suggested them. This allowed for open discussion and a degree of impartiality in the small group work. The discussions informed the remaining analysis and development of overarching themes, as well as the design of the interactive tool (see section 4.5).

4.1.5 Developing an interactive PDF tool

We determined that the primary end users of our overarching themes were researchers (including service user researchers) and research funders with an interest in health and care. We also wanted to ensure they were accessible to patients, carers, service users and other lay users. In order to help the variety of different users navigate the large number of overarching themes, we worked with Design Science[13] to develop a user-friendly, interactive tool. First, we aimed to group the overarching themes into fewer than ten topics, which would serve as meaningful and intuitive entry points to the overarching themes, and allow users to focus on the areas of particular interest to them. This grouping was an iterative process (meaning a repetitive cycle of feedback and revision) involving the Advisory Group and two further PPI workshops in summer 2022. The purpose of these PPI workshops was to show

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[12] Caulfield, J. (1651777308). How to Do Thematic Analysis | Guide & Examples. Scribbr. Retrieved 31 October 2022, from https://www.scribbr.co.uk/research-methods/thematic-analysis-explained/

[13] Design Science are a design company specialising in science, education and healthcare: https://www.design-science.org.uk/

participants of the previous PPI workshop how their work had influenced our analysis and findings, and to seek their feedback on the draft topics and our plan for the tool.

We explored various options for the tool and settled on an interactive PDF linking out to underlying data (lists of priorities, PSPs and HRCS Health Categories underpinning each theme). The draft tool was reviewed by nine members of the advisory group and six other potential users including health and social science researchers, members of NIHR Research Design Service, and a PPI professional. They provided general and page-specific feedback via a structured form. Based on this feedback, several aspects of the tool were revised including content, layout, language and graphics.

4.6 Findings

We established seven umbrella topics (quality of life; caregivers and families; causes and prevention; screening and diagnosis; treatment and management; services and systems; social influences and impacts), which included a total of 89 overarching themes and sub-themes. These are listed as a taxonomy (a scheme of classification) below.

Taxonomy of overarching themes

1. **Quality of life**
    - 1.1. General quality of life
        - 1.1.1. Understanding the impact of conditions on general quality of life
        - 1.1.2. Improving and maintaining general quality of life
    - 1.2. Psychological and emotional wellbeing
        - 1.2.1. Understanding psychological and emotional wellbeing
            - 1.2.1.1. Understanding psychological and emotional impacts of conditions
            - 1.2.1.2. Understanding psychological and emotional impacts of treatments
        - 1.2.2. Improving and maintaining psychological and emotional wellbeing
    - 1.3. Social and economic wellbeing
        - 1.3.1. Understanding social and economic impacts of conditions (also 7.2)
        - 1.3.2. Supporting participation and integration in society (also 7.3)
            - 1.3.2.1. Supporting work and employment (also 7.3.1)
    - 1.4. Physical functioning
        - 1.4.1. Understanding the impacts of conditions on physical functioning
        - 1.4.2. Reducing the impacts of conditions on physical functioning

2. **Caregivers and families**
    - 2.1. Empowering caregivers and families
    - 2.2. Understanding the influence of family (also 3.1.3.1 and 7.1.1)
    - 2.3. Understanding the impact on caregivers and families
    - 2.4. Supporting the wellbeing of caregivers and families
    - 2.5. Improving professional engagement and communication with caregivers and families

3. **Causes and prevention**
    - 3.1. Understanding the causes of health conditions and health behaviour
        - 3.1.1. Understanding biological mechanisms and influences on health
            - 3.1.1.1. Understanding genetic influences
            - 3.1.1.2. Understanding hormonal influences
        - 3.1.2. Understanding psychological influences on health
        - 3.1.3. Understanding social influences on health and health behaviour (also 7.1)

3.1.3.1. Understanding the influence of family (also 2.2 and 7.1.1)
3.1.4. Understanding environmental and lifestyle influences on health
3.1.5. Understanding how and why a condition progresses
3.1.6. Understanding how conditions affect various population groups differently
3.2. Preventing health conditions from (re)occurring
3.2.1. Modifying lifestyle for prevention
3.3. Understanding and preventing multi-morbidity

4. **Screening and diagnosis**
   4.1. Reducing time to diagnosis
   4.2. Finding the best test, tool or method for screening and diagnosis
      4.2.1. Non-invasive techniques (unspecified)
      4.2.2. Imaging techniques
      4.2.3. Blood tests

5. **Treatment and management**
   5.1. Improving communication and information sharing between people with lived experience and professionals
      5.1.1. Enabling and improving shared decision-making
   5.2. Identifying and evaluating treatments and therapeutic interventions
      5.2.1. Identifying and developing new treatments
         5.2.1.1. Identifying and developing pharmaceutical treatments
         5.2.1.2. Identifying and developing cellular and gene therapies
         5.2.1.3. Finding a cure
      5.2.2. Evaluating treatments and therapeutic interventions
         5.2.2.1. Finding the best treatment, therapy or management strategy
         5.2.2.2. Evaluating the cost effectiveness of treatments and interventions
         5.2.2.3. Evaluating the benefits and risks of pharmaceuticals
         5.2.2.4. Evaluating the benefits and risks of cellular and gene therapies
         5.2.2.5. Evaluating the benefits and risks of medical devices
         5.2.2.6. Evaluating the benefits and risks of surgical interventions
         5.2.2.7. Evaluating the benefits and risks of psychological and behavioural interventions
         5.2.2.8. Evaluating the benefits and risks of physical interventions
         5.2.2.9. Evaluating the benefits and risks of digital technologies
         5.2.2.10. Improving how interventions are evaluated
   5.3. Monitoring, predicting and preventing disease
      5.3.1. Monitoring and assessing disease
      5.3.2. Preventing deterioration and complications
      5.3.3. Predicting deterioration, complications and treatment response
   5.4. Improving self-management of conditions
      5.4.1. Modifying lifestyle for self-management
         5.4.1.1. Using diet to manage health
         5.4.1.2. Using exercise to manage health
   5.5. Tailoring care to individuals or subgroups
      5.5.1. Managing frailty
   5.6. Managing symptoms and side effects
      5.6.1. Managing pain
      5.6.2. Managing fatigue

        - 5.6.3. Managing side-effects of treatment
    - 5.7. Improving rehabilitation following injury or surgery
    - 5.8. Considering or avoiding surgery
    - 5.9. Managing multi-morbidity
        - 5.9.1. Managing physical and mental co-morbidity

6. **Services and systems**
    - 6.1. Optimising multi-agency and multi-professional coordination
    - 6.2. Ensuring safety
    - 6.3. Improving access to services
    - 6.4. Achieving holistic / person-centred care
        - 6.4.1. Improving palliative and end-of-life care
    - 6.5. Understanding and reducing delays / waiting times
    - 6.6. Improving how health information is recorded
    - 6.7. Training and developing professionals

7. **Social influences and impacts**
    - 7.1. Understanding social influences on health and health behaviour (also 3.1.3)
        - 7.1.1. Understanding the influence of family (also 2.2 and 3.1.3.1)
    - 7.2. Understanding the social and economic impacts of conditions (also 1.3.1)
    - 7.3. Supporting participation and integration in society (also 1.3.2)
        - 7.3.1. Supporting work and employment (also 1.3.2.1)
    - 7.4. Addressing health inequalities
    - 7.5. Investigating public awareness and attitudes

The seven topics are not mutually exclusive, but can be considered different “windows” into the overarching themes and PSP priorities, or different ways of grouping them. They sometimes overlap, with six overarching themes appearing under more than one of the seven topics. For example, “Understanding the influence of family” appears under three major themes: “Causes and prevention”, “Caregivers and families” and “Social influences and impacts”.

The umbrella topics, overarching themes and underlying data can be explored using our interactive PDF tool, accessed here.

5. Recommendations and Implications

Based on our findings and experiences of carrying out this project, we have several recommendations listed below. These are separated into recommendations for JLA PSPs (relating to the provision of information) and recommendations for researchers, funders and others wishing to address or otherwise use PSP priorities.

5.1 Recommendations for JLA PSPs

In addition to the “mandatory” documents listed on the JLA website, we recommend that JLA PSPs publish the following information on the JLA website, to aid those wishing to address or otherwise use the research priorities:

1. For each Top 20-30 priority, an **explanatory note** written in lay language, to aid understanding and interpretation of the priority. See the Occupational Therapy and Multiple Conditions in Later Life PSPs for examples. Explanatory notes should now be included in the published Data Management Spreadsheet.
2. For each Top 20-30 priority, the **HRCS** Health Category/Categories and Research Activity/Activities which best reflect the focus of the priority (see Appendix C for guidance). This will help anyone in future wishing to describe the nature of JLA PSP priorities, or to extract all priorities coded under a certain category. These categories should be included in the PSP’s Data Management Spreadsheet.
3. A **project report** giving a full page to each Top 10 research priority, including contextual and explanatory information. See the Autism and Epilepsy (Canada) project reports for examples.
4. A **Data Management Spreadsheet** in locked Excel format, including (clearly labelled) “out of scope” and “already answered” questions.
5. A spreadsheet of **anonymised responses from the harvesting survey**, including respondent demographic data. For example, see this Acne PSP data sheet.

5.2 Implications for researchers, funders and others wishing to use PSP priorities

1. Part 3 of our project aimed to identify overarching themes which could help steer decisions about what to research and what research to fund. To aid use of the overarching themes, we have summarised them in an interactive PDF tool which is available to all via the University of Oxford website. The tool includes links to the priorities, PSPs and Health Categories underpinning each theme.
2. When using specific PSP priorities to make decisions about research questions and research funding, we recommend using all the available information about each priority to understand it as fully as possible. This includes the explanatory note and examples of original uncertainties, which may be hyperlinked to PSP priorities on the JLA website, included in the PSP final report, and/or included in the Data Management Spreadsheet.
3. We have provided guidance for anyone wishing to code PSP priorities using the Health Research Classification System (see Appendix C), and our coding for UK-based PSP priorities published between 2016-2020 is available on the JLA website. If coding for research purposes, we recommend involving three independent coders in anticipation of high levels of disagreement (see our description of coding in section 3.1). All coders should undergo a training period including thorough familiarisation

with the online HRCS guidance and discussion to understand and resolve early discrepancies.

6. Strengths and limitations of the project

This project is the first of its kind to systematically map and characterise information published by JLA PSPs. Its greatest strengths are the sheer quantity and breadth of the PSPs and research priorities included in our analyses (spanning all HRCS Health Categories and Research Activities), and the rigorous process of coding and identification of overarching themes by a multi-disciplinary team. We also involved a diverse group of service users in the analysis of research priorities; this greatly enriched the process and ensured that several important topics were included in our overarching themes: caregivers and families, quality of life including psychological wellbeing, holistic/person-centred care, information sharing, health inequalities and shared decision making.

However, it is important to be mindful that our analyses, particularly Parts 2 and 3, focused on a cross-section of PSPs which published their priorities within a 5-year window. It does not include more recent PSPs, or older PSPs which may have provided rich opportunities for identification of overarching themes, such as the Palliative and End of Life Care PSP (published in 2015). Likewise our Part 1 findings provided a snapshot of the availability of PSP information in early 2021; some of this may since have changed or been updated.

To aid accurate coding of research priorities, we referred to extra information about the priority (explanatory note, examples of original uncertainties and/or project report) where available. However, for many PSPs this information was not available, leaving coders to rely on their own understanding of the priority. It is therefore possible that some of the research priorities were not assigned the most appropriate code. We hope to have reduced this likelihood by having two coders independently coding each priority. The identification of overarching themes was a highly creative process which will have been influenced by the analysts' backgrounds, experiences and perspectives. Again, the involvement of two team members in the inductive analysis of each dataset will have reduced the influence of any single person and the likelihood of important themes being overlooked.

Finally, our overarching themes are only as robust as the Top 10 research priorities underpinning them. During our PPI workshops, some service users highlighted the relative lack of research priorities addressing issues of particular importance to under-represented or non-traditionally engaged communities, and some with experience of participation in JLA PSPs were critical of the lack of diversity among those PSP participants. It was suggested that a broader range of themes might have been identified if PSP participants included more people from communities not usually engaged in research. The JLA acknowledges this and is currently working with PSPs to encourage more diverse participation in PSP Steering Groups and in the community of people who submit and prioritise uncertainties. Some service users also queried the process of transformation of original uncertainties (gathered in the harvesting survey) to final Top 10 priorities, saying it was sometimes difficult to see the link between the two. This process of transformation is led by the PSP's information specialist (the person who combines original uncertainties to create "summary questions" which are then prioritised), whose background likely influences the way they group uncertainties, and who in turn will have shaped the type of overarching themes we were able to identify. The PSP Steering Group also plays an important role in ensuring that the summary questions are an accurate representation of the original submissions, and Steering Groups are made up of representatives from the community of interest.

7. Conclusions

In this project, we have demonstrated that information from a large number of PSPs can be pooled and used for research. We have shown that the Health Research Classification System can be applied to PSP priorities and used to describe the areas of health and types of research highlighted by these priorities. We found that PSP priorities collectively cover the full range of health categories. They are most commonly concerned with treatment, care or services, with a smaller proportion focusing on causes, prevention and diagnosis of conditions. In line with these findings, the largest overarching topic we identified was “treatment and management”. This sits alongside six other overarching topics (each containing multiple overarching themes): quality of life; caregivers and families; causes and prevention; screening and diagnosis; services and systems; social influences and impacts. In total, we identified 82 overarching themes and sub-themes within these topics, which are summarised in an interactive PDF tool. We hope this tool will be used by health researchers and research funders to inform decisions about which topics to prioritise.

Contact

We welcome any feedback: please contact lead author Joanna Crocker at joanna.crocker@phc.ox.ac.uk.

Appendices

Appendix A: Abbreviations

COMET	Core Outcome Measures in Effectiveness Trials
HRCS	Health Research Classification System
JLA	James Lind Alliance
NIHR	National Institute for Health and Care Research
PPI	Patient and Public Involvement
PSP	Priority Setting Partnership

Appendix B: Information Guide

This table shows the different types of PSP information present on the JLA website and captured in our inventory. Unless otherwise stated in the Description column, each PSP was coded ‘Yes’ when information present or ‘No’ when information absent.

Information type (field)	**Description**	**Format**	**Location on JLA website**	**Relevant JLA Guidebook Chapter**
Country	PSP country (including distinction between UK four nations, where relevant)	HTML	PSP webpage	N/A
Date	Date (month and year) Top 10 research priorities published on JLA website. ‘Ongoing’ if prioritisation not yet complete.	HTML	PSP webpage	N/A
Funder	‘Yes’ if funder of PSP clearly stated on PSP webpage; ‘No’ if no mention of funder (or only ‘coordinated by…’); ‘Unclear’ if states ‘supported by…’.	HTML	PSP webpage	3
Protocol	PSP protocol showing what the PSP plans to do, including: purpose; aims and objectives; scope; list of project personnel, Steering Group members and partners; PSP methods; dissemination plan. Based on a template downloadable from JLA website Mandatory for current PSPs.	HTML or PDF	PSP webpage (under ‘Key documents’)	4
Steering Group Terms of Reference	PSP Steering Group Terms of Reference showing what the PSP Steering Group agrees to do and who they are. Based on a template downloadable from JLA website. Mandatory for current PSPs.	PDF	PSP webpage (under ‘Key documents’)	4
Data Management Spreadsheet / Final datasheet (name can vary)	PSP data management spreadsheet which aims to give researchers and funders more information to help identify how to address the questions. Shows all uncertainties received by the PSP, linked to original survey submissions, source (respondent group) and relevant published evidence. In addition, for uncertainties discussed at the final workshop: the final workshop ranking and an explanatory note. Latest version includes two separate worksheets: ‘All questions data’ and ‘Detail for workshop questions’. Most PSPs do not include out-of-scope questions in the spreadsheet, but some (probably a minority) include questions already answered by research.	Excel or PDF (note PDF format obscures data if Excel cells not wrapped)	PSP webpage (under ‘Key documents’ or ‘Top 10 priorities’)	5-8

	Based on a template downloadable from JLA website. Mandatory for current PSPs.			
Engagement Summary	PSP Engagement Summary showing how many people got involved in the PSP and what types of people they were. Includes number of patients/carers and healthcare professionals who took part in harvesting survey, interim prioritisation survey and final workshop. Based on a template downloadable from JLA website. Mandatory for current PSPs.	HTML or PDF	PSP webpage (under ‘Key documents’)	9
Question Verification Form	PSP Question Verification Form showing how the PSP checked that its questions were unanswered. Based on a template downloadable from JLA website. Based on a template downloadable from JLA website. Mandatory for current PSPs.	HTML or PDF	PSP webpage (under ‘Key documents’)	6
Flow chart	Flow chart of PSP process. Alternatively called ‘Process outline’.	PDF	PSP webpage (under ‘Key documents’)	4
Timeline	Planned timeline of PSP activities (Gantt chart)	Excel or PDF	PSP webpage	4
Harvesting survey	Harvesting survey used to gather uncertainties. Alternatively referred to as the ‘initial survey’, ‘survey form’ or similar.	PDF	PSP webpage (under ‘Key documents’)	5
Easy read harvesting survey	Easy read version of harvesting survey	PDF	PSP webpage (under ‘Key documents’)	5
Interim survey	Interim prioritisation survey used to shortlist summary questions for final workshop. Sometimes referred to as ‘Interim ranking form’, ‘shortlisting survey’ or similar.	PDF	PSP webpage (under ‘Key documents’)	7
Easy read interim survey	Easy read version of interim survey	PDF	PSP webpage (under ‘Key documents’)	7
Pre-workshop question ranking form	Participant worksheet showing the shortlist of questions (not in ranked order, with an alphabetised reference for each question). This should include clear instructions asking participants to rank all of the questions before the workshop, bring the list with them, and be prepared to discuss them on the day	PDF	PSP webpage (under ‘Key documents’)	8

Workshop guide	Plain language guide to final workshop, emailed to participants a week before workshop.	PDF	PSP webpage (under 'Key documents')	8
Workshop agenda	Final workshop agenda for participants	PDF	PSP webpage (under 'Key documents')	8
Workshop question cards	Final workshop cards, each showing one of the shortlisted questions/topics for consideration	PDF	PSP webpage (under 'Key documents')	8
Top 10 list	Ranked list of Top 10 PSP priorities, published on JLA website	HTML	PSP webpage (under 'Top 10 priorities')	8
Top 10 extra	Sometimes, each Top 10 priority is hyperlinked to a table of additional information about the priority and PSP (note this is no longer done; extra information is now included in a PSP's Data Management Spreadsheet)	HTML	PSP webpage (under 'Top 10 priorities')	8
Top 20-30	Ranked list of all priorities (usually 20-30) discussed at final workshop.	HTML	PSP webpage (under 'Top 10 priorities')	8
Final report	PSP's own report of its findings, published on JLA website. Reports vary in length and content. Some focus specifically on the final workshop.	PDF	PSP webpage (under 'Key documents') and/or Final reports webpage	9
Journal article	PSP protocol and/or findings, published in an academic journal. Often includes a 'data sharing statement' towards the end of the article.	HTML/PDF	Articles and Publications webpage	9
Other publications	Other publications (not journal articles) used by PSP to communicate findings and listed on JLA website e.g. blog, infographic, newsletter, video, poster. Note that links have not been checked.	Any	Articles and Publications webpage and/or PSP webpage (under 'Key documents')	9

Promotional material	Materials used to promote harvesting survey e.g. poster, flyer, postcard, invitation letter/email, information sheet, press release, video, social media adverts	HTML/PDF	PSP webpage (under ‘Key documents’)	5
Website	‘Yes’ if link to external PSP website present (note some links may no longer work or websites may not be active). External PSP websites may include general intro to PSP process, aims, scope, graphics or details about initial and interim surveys and top 10. Further info about JLA, Funders, steering group and workshop. Meet the team and contact details.	HTML	PSP webpage	N/A
Further work	Further work undertaken with identified research priorities (e.g. developing them with different people or encouraging researchers to set up investigations in those areas), listed on JLA website.	HTML	'Working with the priorities' webpage	10
Funded research	Funded research that has come about as a direct result of identified priorities, listed on JLA website	HTML	'Funded research' webpage	11
Out of scope questions	List of uncertainties/questions gathered by the harvesting survey but considered ‘out of scope’ of the PSP. Separate from Data Management Spreadsheet, which may also include out-of-scope uncertainties.	PDF	PSP webpage (under ‘Key documents’)	5
Any other information sources?	Any other documents or discreet information sources on PSP webpage not already captured in the above fields	Any	PSP webpage	N/A

Appendix C: Guidance for coding JLA PSP priorities using HRCS

We recommend that whoever does this makes full use of the HRCS introductory resources and Guidance, familiarises themselves thoroughly with the frameworks, and follows our guidance below. A second person should be involved to corroborate/query coding decisions.

General rules

- Code clear themes/concepts only. If in doubt about the relevance of a secondary/tertiary code, either don't use the code or flag it for discussion with your team.
- Try to code each concept within a priority only once, by choosing the 'best fit' (rather than assigning two different codes to the same concept). Use additional codes when the priority clearly contains two or more relevant concepts which have roughly equal importance.

HRCS Health Category

Definitions of each Health Category can be found here: https://hrcsonline.net/health-categories/

- Use one or two codes which best fit the PSP as a whole.
  - ➢ E.g. the Diabetes and Pregnancy PSP would be assigned two codes: "Metabolic and Endocrine" and "Reproductive health and childbirth".
- Health Categories should **not** be assigned to reflect mechanisms of pathogenesis or the site of a disease. Choose the Health Category associated with the purpose of the investigation or the overarching main disease.
  - ➢ E.g. the Neuro-oncology PSP would be coded under "Cancer and neoplasms", **not "**Neurology".
- Use additional codes if there are other areas of health or disease referred to in the question / research priority.
  - ➢ E.g. In the Multiple Conditions in Later Life PSP, priority 8 "What are the most effective, cost effective and acceptable interventions to improve the psychological wellbeing of older people with multiple conditions?" would be coded under "Mental Health" (as well as "Generic Health Relevance" due to the PSP topic).
- For non-health related PSPs or priorities, select 'Disputed Aetiology and Other' in the appropriate field.

HRCS Research Activity

These codes should reflect the type of research activity required to address the research priority. There are 8 overarching codes and 48 subcodes, defined here: https://hrcsonline.net/research-activities/ General information about assigning Research Activity can be found here: https://hrcsonline.net/getting-started/general-approach-to-coding/assigning-research-activities/

- Use the minimum number of codes to reflect the focus of the research priority. Use multiple codes only if you feel they should be given roughly equal weight/importance. For example:

    - “How can the best treatment for each individual patient with pancreatic cancer be identified (e.g. regarding surgery and chemotherapy)?” would be coded as 7.3 (Management & Decision Making) only (**not** 6.7 Surgery and 6.1 Pharmaceuticals).

    - “How can adverse effects and long-term damage from medicinal treatment be avoided?” is coded 7.1 (Individual care needs, which includes management of side-effects), **not** 6.1 Pharmaceuticals.

- Use full information on subcode webpage (including ‘Main inclusion criteria’ and ‘Advice on research activities’) to make coding decisions.
- If there is insufficient detail to assign a subcode, use the most relevant overarching code.
    - E.g. "What is the cause of pregnancy hypertension (including pre-eclampsia)?" would be coded under 2 (Aetiology).
- If the question fits **two** possible subcodes under one overarching code, use both subcodes. If the priority fits **more than two** possible subcodes under an overarching code, use the overarching code instead. E.g.:
    - “How can patients’ choices and shared decision making be enhanced?” would be 7.1 (Individual care needs) and 7.3 (Management and decision making).
    - “What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?" Could include subcodes 2.1, 2.2, 2.3 and/or 2.4, so would be coded as 2 (Aetiology).

Advice on using specific Research Activity codes:

- If there are non-health related priorities, or elements of priorities, which fall outside the scope of the HRCS Research Activity framework, code as ‘Other’.
    - E.g. for DCM PSP, “What strategies can be used to increase awareness and understanding of DCM amongst healthcare professionals and the general public?” would be coded as 7.3 (Management and decision making) **and** Other (to capture the general public element).
- Code 1 is for normal processes including ageing and pregnancy not linked to a condition or service use. E.g.:
    - “What are women’s experiences of labour and childbirth?” would be coded as 1.1.

    - “What are the experiences of women using obstetric services?” would be coded as 8.1 (which includes evaluation of service user experiences).

- Code 2 is for aetiology including development of disease.

    - E.g. “What is the natural history of degenerative cervical myelopathy?” would be coded as 2.

- Code 3 is for primary prevention only i.e. in healthy people or ‘at risk’ people without a pre-existing condition. It excludes secondary prevention research which will usually be under 6 (Treatment Evaluation) or 7 (Disease Management). E.g.:
    - “How can pregnancy hypertension (including pre-eclampsia) be prevented in a subsequent pregnancy?" would be coded under 3 (Prevention) because women with a history of hypertension are ‘at risk’ but no longer have an abnormal condition.
    - “How can we predict and prevent shorter term complications of pregnancy hypertension (including stillbirth, fetal growth restriction, neonatal death, progression to pre-eclampsia)?” would be coded under 7.1 and 7.3, because this question is about preventing complications of an existing condition.
- When ‘management strategy’ is referred to in a priority, this does not necessarily mean treatment, so consider coding under 7 (Management of Diseases and Conditions) rather than 5/6 (Development/Evaluation of Treatments and Therapeutic Interventions).
- When ‘treatment’ is referred to in a priority, this does not necessarily mean pharmaceutical treatment. Consider using overarching codes 5 or 6 (Development or Evaluation of Treatments and Therapeutic Interventions) rather than subcodes 5.1 or 6.1 (Development or Evaluation of Pharmaceuticals).
- Unspecified ‘topical’ products should generally be classed as pharmaceutical (5.1 or 6.1) and **not** complementary (5.8 or 6.8).
- Evaluation of nutritional supplements used as treatment for disease should be coded as 6.1 (Pharmaceuticals), **not** 3.3 (Nutrition and Chemoprevention).
    - E.g. “Does nutrition influence the survival and/or quality of life of patients with pancreatic cancer?” is coded as 6.1.
- When a priority is primarily focused on cost-effectiveness of a therapeutic intervention or management strategy, this should be coded under 8.2 (Health and welfare economics) as well as 6 (for therapeutic interventions) or 7 (for management strategies).
- Code 7.1 (individual care needs) includes studies assessing social care or health service needs. Code 8.1 (organisation and delivery of services) is about the provision and delivery of health and care services.
- Code 7.3 (management and decision making) includes studies about the decision making process in diagnosis and prognosis, as opposed to evaluating diagnostic or prognostic techniques (which would fall under code 4 - Detection and Diagnosis).

Appendix D: Stakeholder-generated codes

Table 1: New codes for keyword searching

Code	Source topic[14]	Keywords
Diet	Diet (tailored to specific condition)	Diet, nutrition, food, eat, carbohydrate, fat, protein
Exercise	Exercise (tailored to specific condition)	Exercise, physical activity, active
Pain	Pain	Pain
Fatigue	Fatigue	Fatigue
Health inequalities	Health inequity/inequalities	Vulnerable, groups, under-served, unequal, inequit*, inequalit*. Protected characteristics: age, gender, marital/civil partnership status, disability, pregnancy/maternity, race, religion/belief, sex, sexual orientation.
Surgery	Surgery / surgical interventions	Surg*, operat*, transplant
Delay	Time and time points	Delay, wait*, time
Caregivers & Families	Carer perspective	Carer*, caregiver*, family, families, parent*
Technology	Technology/digital health	Tech*, app*, media, digital, online, on-line, internet, tele*, remote, computer, phone

Table 2: New codes created by combining existing codes

Code	Source topic[10]	How captured
Multi-morbidity	Multi-morbidity	Check priorities coded under Generic Health Relevance or with 2+ Health Category codes
Psychological, social, behavioural & economic determinants of health	Mental health/ psychological well-being; Social determinants of health / healthy life expectancy; Social science angle	Combine HRCS 1.2, 2.3, 3.1, 4.3
Physical environment	Physical environment	Combine HRCS 1.3, 2.2 & 3.2
Pharmaceuticals	Medicines / pharmaceuticals	Combine HRCS 5.1 & 6.1
Surgical interventions	Surgery / surgical interventions	Combine HRCS 5.4 & 6.4
Medical devices	As above	Combine HRCS 5.3 & 6.3
Cellular & gene therapies	As above	Combine HRCS 5.2 & 6.2
Radiotherapy & other non-invasive therapies	As above	Combine HRCS 5.5 & 6.5
Psychological and behavioural therapies	As above	Combine HRCS 5.6 & 6.6

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[14] Original topic suggested by patient/carer/other stakeholder

Physical therapies	As above	Combine HRCS 5.7 & 6.7
Complementary therapies	As above	Combine HRCS 5.8 & 6.8
Resources and infrastructure	Pathway/process/systems engineering, complex systems	Combine HRCS 1.5, 2.6, 3.5, 4.5, 5.9, 6.9, 7.4, 8.5
Research (design, methods, dissemination & implementation)	Evidence-based methods	Combine HRCS 8.3 & 8.4

Table 3: New codes to capture within existing codes

Code	Source topic[10]	How captured
Self-management	Patient self-management	Code within HRCS 7.1
Social	Social determinants of health / healthy life expectancy; Social science angle	Code within HRCS 1.2, 2.3, 3.1, 4.4, 6.6, 7.1, 7.2, 8.1
Place of care	Service delivery / place of delivery	Code within HRCS 8.1
Transitions in care	Service delivery / place of delivery	Code within HRCS 7,8
Psychological risk factors	Mental health/ psychological well-being	Code within HRCS 1.2, 2.3, 3.1, 4.4
Psychological impact of illness	Mental health/ psychological well-being;	Code within HRCS 7.1
Communication & information sharing	Information sharing	Code within HRCS 3.1, 7.1, 7.3, 8.3
Utilising patient/carer expertise	Experts by experience	Code within HRCS 7.1 & 7.3
Shared decision-making	Shared decision-making	Code within HRCS 7.1 and 7.3
Health literacy	Health literacy and education	Code within HRCS 3.1, 7.1 and Other
Health education	Health literacy and education	Code within HRCS 3.1, 7.1, 7.3 and Other
Public knowledge, views, attitudes & behaviour	Implications for wider public	Code within HRCS 2, 3 and Other
Inequality of access	Inequality of access	Code within HRCS 8.1
Smoking	Lifestyle factors	Code within HRCS 1.2, 2.3, 3.1
Alcohol	Lifestyle factors	Code within HRCS 1.2, 2.3, 3.1
Substance misuse	Lifestyle factors	Code within HRCS 1.2, 2.3, 3.1
Sex & sexual health	Lifestyle factors	Code within HRCS 1.2, 2.3, 3.1