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A H@PPI scoping project for The Health eResearch Centre

THE UNIVERSITY OF MANCHESTER

Review of Patient and Public Involvement and Engagement within UK research funding bodies:

requirements, priorities and provisions.

Report prepared by the Health eResearch Centre's Patient and Public (H@PPI) forum:

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1 MAIN FINDINGS, AT A GLANCE

This review aims to provide staff at the Health eResearch Centre with an overview of how different UK research funders make provisions for, prioritise and integrate patient and public involvement (PPI) into their grant funding schemes. This research provides a static 'snapshot' of the current landscape surrounding PPI*. Therefore, this is only intended to be used as a broad guide and researchers are advised to consult individual funding bodies for more details regarding specific PPI requirements relating to individual grant schemes.

Below are the main results of this research in tabular format for ease of comparison. The headings included address the following questions::

- Do applications regularly require lay documentation? For example, a lay summary or abstract.
- Are applications reviewed by a panel of lay experts? This can be thought of as an indication as to whether your lay documentation will be used in the grant review process.
- Do applications request a statement of PPI involvement? For example the NIHR is committed to adding value to research, doing so by ensuring patients and the public are involved in every stage of the research pathway. This means that applications which have been critically reviewed by a panel of lay experts prior to application submission may be favoured.
- Are financial provisions provided outside of the application process, i.e. is support available to involve patients and the public in pre-application activities?
- Is non-financial PPI support offered and, if so, what form does this take?

It is of note that when discussing activities eligible for both financial and non-financial support, application forms and guidance may refer to either involvement or engagement depending on the funding body consulted. Although, in practice, involvement and engagement are often seen as distinct**, this convention is not observed by all funders reviewed here. Therefore we recognise that in some cases, even though provisions are listed as existing to support engagement, these could also practically be used for involvement activities.

For further details of individual funder requirements please see the appendix at the end of this document.

* Document compiled November 2017

**Patient and public involvement is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants. This goes beyond what many recognise as public engagement. Engagement being traditionally thought of as raising awareness of research, sharing knowledge and/or creating a dialogue with the public. However, we also recognise that practically there can often be significant overlap between what is defined as engagement and what is referred to as involvement.

1.1 SUMMARY OF FINDINGS

Table1: PPI requirements, priorities and provisions by research funder

Research funder	Lay documentation	Lay committee review	Pre-application PPI suggested	Financial provisions outside grant application	Non-financial PPIE support
Alzheimer's Research UK	Yes	Yes	No	No	No
Alzheimer's Society	Yes - 4 page lay application	Yes	Yes - provisioned for through Research Network	No	Yes
Arthritis Research UK	Yes	Yes	No	Yes - only available to current grant holders	Yes
BBSRC	Yes	No	No	No	No
British Heart Foundation	Yes	Yes - clinical trials only	Yes - clinical trials only	No	Yes - promoting involvement opportunities within their network
Cancer Research UK	Yes	Yes (Only some)	No	No	Yes - advertising opportunities through involvement network
Diabetes UK	Yes	Yes	Yes	No	Yes - guidance documents available, plus help advertising opportunities
EPSRC	Yes	No	No	Yes (engagement))	No
Kidney Research UK	Yes	No	No	No	No
MRC	Yes	No	No	Yes (engagement)	Yes (engagement skills training)
NIHR	Yes	Yes	Yes	Yes	Yes - through INVOLVE
The Wellcome Trust	Yes	No	No	Yes (engagement)	Yes (engagement)

2 LIST OF ACRONYMS:

ARUK: Arthritis Research UK
BBSRC: Biotechnology and Biological Sciences Research Council
BHF: British Heart Foundation
CRUK: Cancer Research UK
EPSRC: Engineering and Physical Sciences Research Council
KRUK: Kidney Research UK
MRC: Medical Research Council
NIHR: National Institute for Health Research
PPI: Patient and public involvement.
PPIE: Patient and Public Involvement and Engagement

3 INTRODUCTION:

The aim of this review has been to gain a better understanding of how UK research funders, likely to be accessed by HeRC researchers, prioritise, value, require and make provisions for PPIE within their grant funding schemes. This project was undertaken by HeRC's PPIE group H@PPI and is intended as a resource for researchers looking to build PPIE into new grant applications and existing projects.

The result of this work will signpost available sources of funding for PPIE and give an overview of the requirements different funding bodies have in relation to PPIE.

3.1 OUR APPROACH

Our project has focused on 12 UK funding bodies. The following were chosen since these funders have historically been accessed by HeRC researchers and are also likely to be accessed in the future.

- Arthritis Research UK (ARUK)
- Alzheimer's research UK
- Alzheimer's Society
- Biotechnology and Biological Sciences Research Council (BBSRC)
- British Heart Foundation (BHF)
- Cancer Research UK (CRUK)
- Diabetes UK
- Engineering and Physical Sciences Research Council (EPSRC)
- Kidney research UK
- Medical Research Council (MRC)
- National Institute for Health Research (NIHR)
- Wellcome Trust

We reviewed the websites of each funder, probing their approach to PPI including, what they expect from researchers in regard to PPI input for grant applications, whether they have financial provisions for PPI and the roles lay members play on their own reviewing panels. Specifically, we attempted to answer the following questions:

- Are applicants expected to submit any documentation aimed at a lay audience as part of their application and are patients/lay members involved in funding decisions?
- Do they offer separate funds to facilitate PPIE? Are there provisions to build PPI into grant applications, i.e. to facilitate involvement at the grant application stage?
- Do they mention public priority setting anywhere on their website?

Alongside this we also asked the following broad questions regarding their funding models:

- How much does the organisation spend on research each year?
- What type of research do they fund?
- What health conditions does their research cover?
- Has the organisation identified any research priorities and do these align with local or national public priorities?
- Do they commission research on specific topics?

Following our website reviews, if answers to these questions were unclear, we followed up by e-mailing specific questions to funder representatives. Full tabular findings from this review can be found in the appendix at the end of this document.

4 SUMMARY OF FINDINGS

1. Research funders unanimously recognised the importance of public involvement and engagement.
 - a) All 12 research funding bodies reviewed in this exercise made reference to the importance of either patient and public involvement and/or engagement on their websites. The majority (n=8) specifically acknowledged the benefits of actively involving the public in research (involvement) while the remaining (n=4) focussed more on the benefits of engaging with the public. Here is one representative example from Kidney Research UK's website: *"Our work is vastly improved through patient involvement. Having the patient and carer 'voice' means we have input from the people who matter most, those who have first-hand experience, which is vital to achieving research breakthroughs"*. Most other research funders shared the same sentiment.
2. All research funders expect applicants to include a lay summary or abstract as part of their grant application.
 - a) All of the funders surveyed required grant applicants to complete some form of lay abstract or project summary as part of the application process. The length and detail required for these lay summaries varied between funders (see appendix for individual funder details).
 - b) **HeRC's PPI team and the H@PPI forum are available to support researchers in writing effective lay summaries for their upcoming grant applications. For more information contact sarah.fox-3@manchester.ac.uk**
3. Most ($n = 7$) research funders involve lay members of the public in their grant peer review process. In these cases it is assumed that the comments of lay reviewers are likely to influence the outcomes of funding decisions.
 - a) We noted that the following research funders include lay representation on their grant review boards:
 - i. Alzheimer's Society: All applicants are asked to provide a 4 page lay application to aid the lay review process.
 - ii. Alzheimer's Research UK: Grant review board meetings regularly include lay representation.
 - iii. Arthritis Research UK: Applications are reviewed by lay members of the patient insight partnership before funding decisions are made.
 - iv. British Heart Foundation: All Clinical Studies will be subject to lay review by the Clinical Studies Committee which contains lay members.
 - v. Cancer Research UK: Some but not all funding committees include patient representation.

- vi. Diabetes UK: applications are reviewed by a lay panel and give a priority before being sent to research committee for judgement. Note: research committee also contains lay members.
 - vii. National Institute for Health Research: Applications are reviewed by a range of experts, clinicians, patients and carers
4. Four funders stated that they value patient input throughout the research process (from inception to completion) and, therefore they required applicants to include a statement explaining how patients and the public were involved in developing/designing their project. These funders include:
- a) Alzheimer's Society: *"Alzheimer's Society offers researchers the opportunity to seek the input of our Research Network volunteers prior to submitting an application for funding. We are particularly keen to provide patient and public involvement support for early-career researchers who are developing their first research application. However, this offer is open to all applicants to our grant rounds."*
 - b) BHF: *"We expect applicants to actively involve patients and the public in the design and conduct of clinical studies and trials. We recognise that the nature and extent of active patient and public involvement will vary depending on the context of each study."*
 - c) Diabetes UK: *"We believe that involving people affected by diabetes in the development of grant applications produces higher quality, more relevant research, which is more likely to receive funding."*
 - d) NIHR: *"You should involve the public from the outset and ensure that your research intention is clear for those outside your professional specialty reviewing your application by providing a good quality, plain English summary."*
5. Five funders stated that they specifically used priority setting exercises to inform their own research priorities, which enabled patients, carers and health and social care professionals to be involved in the process of identifying and prioritising re-search questions. These included:
- a) Alzheimer's Society
 - b) Arthritis Research UK
 - c) Diabetes UK
 - d) Kidney Research UK
 - e) National Institute for Health Research
6. All research funders reviewed here stated that they would consider reasonable requests for dedicated involvement/engagement costs when these were included within an application.
7. Five funders offer financial support for involvement/engagement initiated outside of a grant application. Specifically:

- a) The EPSRC offer engagement funding via the Holmes Hines Memorial Fund, see [here](#) for more information.
 - b) The MRC offers dedicated engagement funding which can be accessed at any time. More information can be found [here](#)
 - c) As part of the NIHR, researchers who are active in the North West and planning on applying for NIHR funding can apply for a small bursary (up to £300) from the Research Design Service North West. This is designed to facilitate involvement at the pre-grant application stage. More details can be found [here](#)
 - d) The Wellcome Trust also offers dedicated engagement funding, which can be accessed at any time. More information can be found [here](#)
 - e) Arthritis Research UK offers funding for research award holders who have not budgeted for PPI as part of their original grant application but would like to integrate involvement activities into their research. More information on this scheme can be found by contacting the following address: patientinsight@arthritisresearchuk.org.
 - f) **We also recommend that you visit Public Engagement at Manchester's funding round-up page to check for funding opportunities within the University [here](#)**
8. The majority of funders ($n = 9$) offer various forms of non-financial support regarding PPI. This ranged from documentation (handbooks and best practice guides) to hands on help with recruiting and PPI planning. Of note are the following:
- a) The Alzheimer's Society has its own PPI research network who are available to help researchers develop proposals, review lay documentation and participate in PPI activities. More information can be found [here](#).
 - b) ARUK offer PPI and communication training workshops, which are open to all researchers receiving ARUK funding [here](#).
 - c) The BHF offer to promote your study across their networks to help with recruitment, see [here](#) for more details.
 - d) CRUK provide PPI resources and training as well as access to their involvement network which aims to enable their researchers to work with people affected by cancer to develop and deliver research, [link](#). They also offer a prize (£1,000) for good PPI, [here](#).
 - e) Diabetes UK state that they can support you to involve people with diabetes in your research in a meaningful way by advertising your PPI request in their involvement newsletter or putting you in contact with their local groups across the UK. More information can be found [here](#).
 - f) NIHR offer information, guidance and online resources on patient and public involvement in research and the difference it can make, through the INVOLVE Programme [here](#).
9. **We would also like to highlight the support H@PPI and HeRC's PPI team offer researchers:**

- a) **PPI officer Sarah Fox holds clinic sessions every Wednesday between 2 and 4pm where she is available to discuss any involvement-related queries you might have.**
- b) **The H@PPI group host regular 'Critical Friend' sessions where they are available to review grant applications, lay summaries and PPI proposals.**
- c) **For more information on how HeRC and H@PPI could help you please contact sarah.fox-3@manchester.ac.uk**

5 ABOUT THE AUTHORS

HeRC's Patient and Public Involvement (PPI) group H@PPI (HeRC@PPI), formed in 2014, play an integral role in developing and implementing the centre's plans for public involvement and engagement. H@PPI is a panel of public contributors (currently 12) who dedicate their time towards understanding and advising on HeRC's PPI activities, communications and research.

The group meet regularly with the centre's PPI management team to discuss their strategic position, update each other on their independent activities and share knowledge of local and national PPI opportunities. They also regularly collaborate with researchers on projects and advise on funding applications. As part of their collaborative work with the department, the group hope to embed the ethos of meaningful patient public involvement at all levels of HeRC's structure. Therefore, they wish to use this opportunity to highlight PPI requirements and the provisions available to our research staff when applying for external funding.

The H@PPI forum is facilitated by HeRC's PPI lead Dr Sarah Fox and is currently chaired by Grace McCorkle with Alan Campbell as vice-chair.



6 APPENDIX

6.1 ALZHEIMER'S RESEARCH UK.

Yearly Spend	£28m in 2016 'Annual Report': link
Type of research funded	Basic and clinical but not care or service delivery research
Health conditions covered	Alzheimer's disease and other dementias
Identified research priorities	Alzheimer's Research UK funds research into cause, diagnosis/detection, prevention and treatment (disease modifying and symptomatic). Of particular importance is research which has translational potential for patient benefit.
Commissioned research?	Response mode funder, offers a wide range of grant schemes: link . All applications must fall within ARUK's remit.
How funding decisions are made	Do applications include any lay documentation?: 1. Applicants are requested to complete a lay summary of their application. which is sent to lay review volunteers for comments. Advice on writing a good lay summary can be found on their website here. Are lay members involved in reviewing grant applications?: 1. Lay summary is sent to lay review volunteers for comment. The comments made by lay reviewers are made available to the reviewing board members. Note: Grant review board meetings regularly include lay representation. Applications for research studies that involve people all require lay review. Grants are reviewed within distinct advisory groups, depending on the grant scheme applied to and the expertise required to review them.
Are separate PPIE funds available	Not mentioned on website.
Reference to public priority setting	Not mentioned on website

The following questions were posed to Alzheimer's research UK following our website review

1. Do your grant review committees regularly include lay members?
 - a) Yes, our Grant Review Board meeting regularly includes lay representatives.
2. When considering grant applications, do any of your funding schemes require evidence of PPI or researcher's intention to build PPI into their work? If this is not a requirement, are applications which provide evidence of PPI favoured in any way?

- a) None of our grant schemes require patient and public involvement and applications that do are not favoured in any way.
- 3. Do you offer financial support (i.e via grant schemes) to encourage and facilitate researchers who wish to build patient and public involvement into their research and what advice to you offer researchers on the topic of PPIE funding?
 - a) We don't actively encourage researchers to include PPI into their work but when they do, these applications are reviewed by a lay reviewer and given feedback on the PPI part of their application form
- 4. Do you recognise and prioritise topics which align with local and national health priorities? i.e. James Lind priorities.
 - a) We encourage researchers to submit applications which align with our own priorities, 'Of particular importance is research which has translational potential for patient benefit but all applications are treated and reviewed in the same way'.

6.2 ALZHEIMER'S SOCIETY.

Yearly Spend	£10m per year by 2017 link
Type of research funded	Basic and Clinical
Health conditions covered	Research across all areas of Dementia. Also recognition of conditions which overlap with dementia (rheumatoid arthritis, diabetes).
Identified research priorities	Their funding remit is organised into two streams: 1. Biomedical research 2. Care Services and public health research. Research priorities are aligned with James Lind public priorities and two Alzheimer's society staff sit on the James Lind Board - see link
Commissioned research?	Response mode funder for applications aligned with their funding remit, link
How funding decisions are made	Do applications include any lay documentation?: 1. All applications include a 4 page lay application. To aid in the lay review process, Alzheimer's Society offers researchers the opportunity to seek the input of their Research Network of approximately 280 carers, former carers and people with dementia prior to submitting an application for funding. link Are lay members involved in reviewing grant applications?: 1. All grant applications are subject to both peer and lay review processes
Are separate PPIE funds available	Although the website does not state the existence of a separate PPIE funding pot, Alzheimer's Society does offer researchers the opportunity to seek the input of their research network volunteers prior to submitting an application for funding. They state that they are particularly keen to provide patient and public involvement support for early career researchers who are developing their first research application.
Reference to public priority setting	Research priorities are aligned with James Lind public priorities

6.3 ARTHRITIS RESEARCH UK.

Yearly Spend	2014-2015 research spend: £23.0m (figures for 2016-2017 not yet available)
Type of research funded	Research that aims to prevent the onset of arthritis, develop a cure for arthritis and transform the lives of those living with arthritis. - Basic and clinical
Health conditions covered	All conditions which affect the joints, bones and muscles, including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis.
Identified research priorities	Three themes: 1. disease 2. treatment 3. health. New focus for 2020 is to improve the quality of life of people with arthritis.
Commissioned research?	They fund a variety of research from basic laboratory work to clinical trials. Using dedicated funding calls focusing on Key challenges: see here for details of current funding calls.
How funding decisions are made	Do applications include any lay documentation?: 1. Applications require you to submit a lay case for your grant: information on what this should contain can be found here. Are lay members involved in reviewing grant applications?: 1. Applications will be reviewed by lay members of the patient insight partnership before funding decisions are made.

Are separate PPIE funds available	ARUK recognise that involvement may not have been budgeted for in existing grants which can make it hard to start involving patients. Funding is therefore available to research award holders who wish to integrate involvement activities into their research. For more information e-mail patientinsight@arthritisresearchuk.org They also offer PPI and communication training workshops which are open to all researchers receiving ARUK funding see: link A handbook for PPI is also available containing information on: 1. Why you should involve people with arthritis in your research 2. Guidance for basic researchers. 3. Guidance for clinical researchers. 4. Top tips on how to meaningfully involve people with arthritis. 5. Case studies. 6. Useful resources
Reference to public priority setting	ARUK state that the patient voice is integrated fully into all their research activities through close collaboration with their patient insight partners (PIPs). PIPs collaborate on the following activities: 1. Setting research priorities. 2. Supporting researchers to undertake effective public and patient involvement. 3. Reviewing research proposals 4. Monitoring and providing input into funded research. 5. Evaluating and disseminating outcomes of research.

6.4 BIOTECHNOLOGICAL AND BIOLOGICAL SCIENCES RESEARCH COUNCIL (BBSRC)

Yearly Spend	They invested £469 million in biosciences research in 2016-2017
Type of research funded	Broad remit, including: 1. Agriculture and food security 2. Bioscience for health 3. Frontier bioscience 4. Industrial biotechnology 5. bioengineering. They state that they fund “world-class bioscience, people and research infrastructure that helps tackle major challenges such as the impact of climate change, a healthier old age, sustainable food production, land use and energy production.”
Health conditions covered	No specific health conditions but they list four key challenge areas as: 1. Lifelong health: understanding the mechanistic basis of lifespan and healthy ageing using human microbial and animal systems with the lifelong objective of promoting health in later life. 2. Nutrition for health: Understanding how foods, nutrients and whole diets influence cellular processes, how these influences affect overall health outcomes and how responses vary between population groups, individuals and across a life course. 3. One Health: Collaborative and coordinated approaches to combat infectious diseases of zoonotic origin drawing on a common pool of scientific knowledge from multiple disciplines to improve health and wellbeing of animals people and the environment. 4. Biotechnology for health: Development of enabling biotechnology and innovative approaches to support the translation of basic bioscience.

Identified research priorities	As above. Specific priorities listed for responsive mode applications are: 1. Animal health 2. Bioenergy 3. Combatting antimicrobial resistance 4. Data driven Biology 5. Food, nutrition and health 6. Healthy ageing across the life course 7. Integrative microbial research 8. New strategic approaches to industrial biotechnology 9. Reducing waste in the food chain 10. The replacement refinement and reduction of animals in research 11. Sustainably enhancing agricultural production 12. Synthetic biology 13. Systems approach to bioscience 14. Technology development for biosciences 15. Welfare of managed animals 16. Collaborative research with users 17. Research into public policy 18. International partnerships.
Commissioned research?	The Biosciences for health priority is delivered through responsive mode grants, topic-specific initiatives, cross-research council programmes and industrial and international collaborations. The responsive mode strategic priorities in healthy ageing across the life course, food nutrition and health and animal health are of particular relevance to Biosciences for health.

How funding decisions are made	Do applications include any lay documentation?: 1. All applications require a plain English summary with a maximum of 4000 characters and explaining: a) The context of the research b) Its aims and objectives c) Its potential applications and benefits Are lay members involved in reviewing grant applications?: 1. No. Scientific assessment of research quality will be undertaken by UK and overseas experts against the following criteria: a) Scientific excellence b) Industrial and stakeholder relevance c) Relevance to the BBSRC d) Economic and social impact e) Timeline and promise f) Value for money g) Staff training potential. In relation to pathways to impact the BBSRC state: <i>‘researchers need to be actively involved in thinking about demonstrating the value of their research and its wider impacts from its inception to completion - and ideally beyond’</i> they note that <i>‘Public engagement may be included as one element of your Pathway to Impact. Engaging the public with your research can improve the quality of research and its impact, raise your profile, and develop your skills. It also enables members of the public to act as informed citizens and can inspire the next generation of researchers’</i>.
Are separate PPIE funds available	No mention of PPI but notes that they spend £1million on public engagement activities annually. They note that they no-longer offer a small award for PE but that they are working to embed engagement into research grants.
Reference to public priority setting	No

6.5 BRITISH HEART FOUNDATION (BHF)

Yearly Spend	£100 million per year
Type of research funded	Basic and clinical: Includes basic science research, population based cohort studies and studies using datasets only.
Health conditions covered	Cardiovascular disease: wide range of heart conditions, their diagnosis and treatment. Also mentions Stroke/Diabetes as risk factors in cardiovascular disease and does offer some funding in these areas.
Identified research priorities	Response mode funder priorities found here
Commissioned research?	They provide personal support for clinical and non-clinical cardiovascular researchers at all stages of their career. They also provide grants for short and long-term research projects, essential infrastructure and strategic initiatives
How funding decisions are made	Do applications include any lay documentation?: 1. All applicant are asked to provide a lay summary, details of which can be found here 2. They also expect applicants to actively involve patients and the public in the design and conduct of clinical studies and trials. They require evidence of this in research applications and all applications will be assessed by their Patient Advisory Group. Are lay members involved in reviewing grant applications?: 1. They have five research grants committees whose members are experts in basic and clinical cardiovascular research. Only their Clinical Studies Committee contains lay members. Each of their committees meets four times a year other than the Clinical Studies Committee and the Translational Awards Committee which meet twice a year.
Are separate PPIE funds available	No evidence on website.
Reference to public priority setting	No evidence on website

The following questions were posed to The British Heart Foundation following our website review

1. Do you offer specific financial support (i.e via grant schemes) to encourage and facilitate researchers who wish to build patient and public involvement into their research and what advice to you offer researchers on the topic of PPIE funding.

- a) In terms of funding for PPI, we do not offer specific financial support, it is expected that when a funding application is put together, PPI costs are incorporated. We also do not currently offer specific advice on the topic of funding/PPI.
2. Do you recognise and prioritise projects which align with local and national health priorities?
- a) We are a response-mode funder, believing that the most effective way of tackling cardiovascular disease is to allow the research community to identify the gaps in knowledge and generate the research ideas and approaches needed to fill those gaps. We support a broad cardiovascular portfolio of basic science and clinical research, totalling around 1,000 active research grants at any one time.

6.6 CANCER RESEARCH UK (CRUK)

Yearly Spend	£432 million in 2016/2017
Type of research funded	Preventative research, Diagnostic research, treatment and treatment optimisation.
Health conditions covered	All forms of cancer
Identified research priorities	Priority areas for research (Prevent, Diagnose, Optimise): 1. Early diagnosis 2. Lung, pancreatic, oesophageal cancers and brain tumours. 3. Causes and the role of the immune system. 4. Prevention research. 5. New treatments. 6. Increase survival rate ? through precision medicine.
Commissioned research?	Yes, see link
How funding decisions are made	Do applications include any lay documentation?: 1. Applicant will be expected to submit a lay summary with their grant application Are lay members involved in reviewing grant applications?: 1. Peer review is via expert review panels, and in some cases patient representatives are included on funding committees - depending on the nature of the grant.

Are separate PPIE funds available	They state that CRUK firmly believe that working with those affected by cancer increases our understanding of cancer, and that high quality PPI helps that they ensure that the work they fund meets the needs of patients. They provide PPI resources and training, as well as access to their involvement network, which aims to enable their researchers to work with people affected by cancer to develop and deliver research: link Their PPI team are on hand to offer guidance on developing and delivering PPI and PPI opportunities can be advertised through their network (although this is not guaranteed - requests will be reviewed). They also offer a prize (£1,000) for good PPI: link PPI to be built into grant applications, no separate funds available.
Reference to public priority setting	No

6.7 DIABETES UK (DUK)

Yearly Spend	£7 million on new and existing research
Type of research funded	Lab based basic research all the way through to clinical trials.
Health conditions covered	Diabetes and associated complications such as kidney disease and heart disease - current funded projects can be found here
Identified research priorities	Diabetes UK has just carried out a James Lind Alliance Priority Setting Partnership for Type 2 diabetes and these will be published in October, here. One had been done in 2011 for Type 1 diabetes (not by Diabetes UK). They have also just formed the Clinical Studies Groups to identify gaps in diabetes research and build a landscape for diabetes research, these groups will be taking into account the outcomes from the Type 1 and Type 2 JLA PSP.
Commissioned research?	Response mode funder with some strategic calls in areas of need which have been identified.
How funding decisions are made	Do applications include any lay documentation?: 1. A lay summary is required for all applications. They also encourage applicants to include people with diabetes in the development of their application as well as throughout the project. Are lay members involved in reviewing grant applications?: 1. lay panels assess the applications and give a priority, then the Research Committee meet (at which a few lay members are present) to fund the highest quality projects within the budget available. A process diagram is available here
Are separate PPIE funds available	No
Reference to public priority setting	Yes

6.8 ENGINEERING AND PHYSICAL SCIENCES RESEARCH COUNCIL

Yearly Spend	> £800m per year
Type of research funded	The EPSRC fund research on a broad range of topics, including physics, chemistry, mathematics, material science, information technology and structural engineering. Their research provides underpinning knowledge that informs other fields such as the life and medical sciences. EPSRC work with other Research Councils at the boundaries of our remit to ensure there are no gaps in funding, so proposals at the interfaces of traditional research disciplines have the same support structure as those that fall well within Research Council remits.
Health conditions covered	No specific health conditions - their research provides underpinning knowledge that informs other fields such as the life and medical sciences.
Identified research priorities	1. 21st Century products - 'smart'/multifunctional products that might enable or enhance wellbeing. 2. Digital manufacturing - integration of computer-based systems, capturing emerging capabilities from the information and communication technologies research base that can help factories to become 'intelligent' (i.e. highly automated, and in some cases completely autonomous). 3. Sustainable industries - things that help manufacturing industries meet the needs of present sectors/customers without compromising the ability of future generations to meet their own manufacturing needs. 4. New industrial systems - industrial systems that develop to become more effective at creating and capturing value at a variety of scales, at a tangible level (i.e. alternative machine tools, cellular manufacturing, self-healing tools, systems that self-build), different models of operation (i.e. alternative supply chains and business models) or mass customisation (i.e. in consumer products and personalisation of healthcare).
Commissioned research?	Response mode funder

How funding decisions are made	Do applications include any lay documentation?: 1. All applicants are expected to complete a research summary as part of their grant application. It is advised that this summary is written in a style that is accessible to a variety of readers including the general public. Are lay members involved in reviewing grant applications?: 1. No. All funding decisions are based on expert advice from members of the College of Peer Reviewers. The research proposal is first sent out for peer review, and is then sent to a panel. Website does not specify but it appears that the panel is made up of expert researchers. Research Councils UK, encourages applicants to demonstrate how their research impacts on the public and if they intend to undertake engagement activities. However, there are no mandatory requirements regarding involving members of the public and patients and carers in their research study.
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Are separate PPIE funds available	Applicants are encouraged to budget for PPIE within their research proposals as part of a pathway to impact. They focus more on engagement rather than involvement. They suggest that, as part of your proposal, you should consider requesting resources to: 1. Engage with suitable patient groups, e.g. through regular workshops. 2. Develop a patient/public advisory group eg. advertising costs for recruitment or staff time to facilitate this. 3. Include patient representatives in advisory or steering boards. 4. Undertake suitable media training. 5. Development costs of a user friendly outward facing website and social media interfaces. 6. Involve patients or carers in the preparation of your dissemination materials. 7. Present your research to the wider public e.g. at hospitals, schools, science fairs etc. 8. Host laboratory open days for the public.
Reference to public priority setting	No

Quote from website on PPIE: *“Patients and the informed public are the single best source of information about the effects of a disease or condition on the people most intensely affected. The rise of the patient expert, also presents significant opportunities to gain valuable input to the development of your research. Effective public and patient involvement is frequently being recognised as essential across the health sector so developing effective mechanisms for engaging them with your technology will be a significant advantage.”*

6.9 KIDNEY RESEARCH UK

Yearly Spend	> £6.7 million 2016/2017
Type of research funded	1. Kidney Transplant in Children 2. Life expectancy for Children on Dialyses 3. Urinary Tract Infection, Superbug 4. Iron deficiency and Anaemia 5. Longevity of Transplant
Health conditions covered	Kidney disease.
Identified research priorities	Understanding of kidney disease, its causes, treatment and management. Increase awareness of kidney health, support early diagnosis and prevention.
Commissioned research?	Both direct and commissioned research
How funding decisions are made	Do applications include any lay documentation?: 1. A lay abstract/summary is required for all applications, if researchers need advice on the format of this summary KRUK is happy to be contacted directly and will strive to answer any questions. 2. Researchers will also be asked to describe how their research will benefit patients. 3. They do not currently ask for evidence of public involvement in the development of research ideas - but, there may be scope for this in the future. Are lay members involved in reviewing grant applications?: 1. No. Peer review is performed by a panel of experts which does not include lay members.
Are separate PPIE funds available	If relevant they expect PPI costs to be budgeted into grant applications and these will be reviewed with other requested costs.

Reference to public priority setting	Yes “we ensure our plans reflected the key research themes emerging from the UK Renal Research Strategy. We also wanted to take account of the outcomes of the patient survey and the priority setting partnership work with the James Lind Alliance on Transplantation” “At Kidney Research UK we are passionate about giving patients and carers a 'voice' in our many approaches to research. We actively engage with and listen to patients so we can better understand what research matters most to them.”
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6.10 MEDICAL RESEARCH COUNCIL

Yearly Spend	Gross research expenditure 2015/16 - £927.8m
Type of research funded	MRC fund a wide range of medical and health research. This includes laboratory, use of animals in research and all aspects of medicine, biology, genetics and theoretical work including methodologies, bio- data.
Health conditions covered	No specific health conditions - their research is broad and aligns with their research priorities listed below.
Identified research priorities	The MRC cover the following science areas: 1. Infections and immunity 2. Molecular and cellular medicine 3. Neurosciences and mental health 4. Population and systems medicine - this includes: cardiovascular, respiratory, maternal health, population studies, medical sociology. 5. Global health 6. Translational research- <i>“Translation is the principle of turning fundamental discoveries into improvements in human health and economic benefit. MRC’s translational aims ? to drive innovation, speed up the transfer of the best ideas into new interventions”</i>
Commissioned research?	Response mode funder: of particular relevance to HeRC The MRC have identified a need for improved methods to better measure human study participant characteristics and their environments - including the development and/or validation of new devices for use at scale in a real world setting, as well as biosensors for continuous personal monitoring.

How funding decisions are made	Do applications include any lay documentation?: 1. All applicants are expected to complete a research summary as part of their grant application. It is advised that this summary is written in a style that is accessible to a variety of readers including the general public. Are lay members involved in reviewing grant applications?: 1. No. MRC boards and panels include scientists and specialists in the field decide what is funded.. But they do state: <i>“We (MRC) seek public input when reviewing major public health and translational research investments, and ensure that the public is actively engaged in key areas, for example on the use of patient data through the Farr Institute for Health Informatics Research”</i>
Are separate PPIE funds available	The MRC have funding available for public engagement. This includes: 1. MRC Public Engagement in Science Activities - Seed Fund. To encourage and support engagement with the public and other stakeholders, funds are available to enable MRC-funded scientists to pilot new activities and develop innovative engagements. 2. MRC Festival of Medical Research 2017 Award - MRC-funded units, centres and institutes participating in the MRC Festival of Medical Research 2017 are entitled to an award of up to £1500 to help cover activity costs. To be eligible for the award, activities must meet the MRC Festival objectives and take place during the Festival period of 17 - 25 June 2017. 3. Alexander Fleming Dissemination Scheme awards by the Medical Research Foundation (MRF) - To fund the dissemination of MRC and MRF-funded peer-reviewed research results beyond the scientific press to patients, research participants, practitioners and policy makers.
Reference to public priority setting	No

The following questions were posed to The Medical Research Council following our website review:

1. Do you have any future plans for public representation in priority setting and strategic planning for MRC funded research? For example do you currently, or intend on forming links with the James Lind Alliance or similar patient priority setting partnerships?
 - a) At the moment the MRC has no plans for priority setting and strategic planning for MRC funded research. If and when these plans materialise, we will consider how best we can take account of public perspectives during the development process. We use a range of mechanisms for accessing public perspectives and we have an MRC Public Panel made up of public volunteers whom we involve in our work from time to time.
2. Do you Plan to include members of the public on funding review boards and panels? If yes, how? If no, what are your reasons?
 - a) At present there are no plans to include members of the public on funding review boards and panels. In 2014 we held two workshops with members of the public and colleagues from the MRC community, particularly those with an interest or involvement in PPI, to consider how best the MRC can involve members of the public in its work. A consensus that emerged from these workshops was that including public or patient representatives in funding decisions is not a suitable model for an organisation that principally support basic research.
3. Do you offer training courses in PPI/E? If so what do these include and have they been developed in partnership with members of the public?
 - a) We offer MRC-funded researchers the opportunity to take part in public engagement skills training sessions (half day or full day) which helps them improve their confidence and skills in communicating with non-scientists and develop techniques for engaging members of the public with their research. We commission professional trainers to run these sessions and I don't know if any of these trainers developed their training sessions in partnership with members of the public.

6.11 NATIONAL INSTITUTE FOR HEALTH RESEARCH (NIHR)

Yearly Spend	Total spend in 2015/16: £1,037 million. Figures can be seen here
Type of research funded	The NIHR commissions and funds health, public health and social care research that is essential for improving the health and wealth of the nation. A key objective is to improve the quality, relevance and focus of the research we commission by distributing funds in a transparent and accountable way through open competition and expert review. The NIHR also funds career development for researchers whose work focuses on people and patient-based applied health research. Current funding opportunities can be found here
Health conditions covered	Very broad
Identified research priorities	Public health: covers research about the evaluation or delivery of interventions intended to improve the health of healthy populations or groups of patients (NB not including research into the causes of health problems). Health services and organisation: covers research that improves patient safety and service organisation. Clinical evaluation and translation: covers evaluations into the efficacy, effectiveness, costs and broader impact of healthcare interventions. Technology development: covers the R&D of any innovative medical technology including medical devices, active implantable devices and in vitro diagnostic devices, and their translation into the clinical environment
Commissioned research?	They offer commissioned, researcher led and themed calls (2017 theme is complex health and care needs in older people).
How funding decisions are made	Do applications include any lay documentation?: 1. Yes, plain English summary is required. Are lay members involved in reviewing grant applications?: 1. Applications are reviewed by a range of experts, clinicians, patients and carers. It is essential that applications are clear and understandable to those outside your profession and that members of the public have been involved from the outset. "All research applicants are asked to describe how they have involved patients and the public in developing their research proposal, as well as plans for involvement in the research study."

Are separate PPIE funds available	They offer information, guidance and online resources on patient and public involvement in research and the difference it can make, through the INVOLVE Programme. Provisions for PPIE should be costed into funding applications. However, they state that “it is considered good practice to involve members of the public as early as possible in the research and design process”. Therefore, researchers active in the North West can apply for a small bursary fund from the Research Design Service North West designed to facilitate involvement at the grant application stage. More details can be found here
Reference to public priority setting	NIHR also head the James Lind Alliance Priority Setting Partnership which agrees research priorities that are of importance to patients and clinicians nationally and internationally. link

6.12 THE WELLCOME TRUST.

Yearly Spend	In 2015-16 they received over 5,000 applications and made 1,461 awards worth £822 million. In the next five years, they aim to spend up to £5 billion across the fields of science, population health, medical innovation, the humanities and social sciences and public engagement.
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Type of research funded	They fund scientific research to improve the quality of health of everyone. This covers all aspects of science ? from molecules and the cells vital to life, to the spread of diseases and vectors of disease around the world, to clinical and public health research. Areas of research include: 1. Biomedical science a) Genetics, genomics and molecular biology: understanding how genes, proteins and other molecules work together to perform the functions of life and what happens when these functions go wrong b) Infectious disease and the immune system: from endemic and epidemic infections, such as malaria and Zika, to the role of the immune system in health and disease c) Cell and developmental biology: how cells function and interact with their environment, and how organisms form, grow and develop d) Physiology and non-communicable disease: how the human body works, and the mechanisms of diseases such as diabetes, obesity and stroke e) Neuroscience and mental health: understanding the brain and mind, and investigating conditions such as dementia, depression and schizophrenia 2. Population health a) Studying how infectious diseases are distributed and transmitted in populations b) Supporting biobanks and cohort studies, which follow individuals over long periods of time c) Improving healthcare systems and education d) Helping translate research into real-world changes that improve people's lives. 3. Humanities and social science: Support ranges from ethnography and the impact of health policy to bioethics and bioarchaeology. a) Product development and applied research b) Public engagement and creative industries
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Health conditions covered	Any health conditions that fit into the broad areas: 1. Genetics and molecular science 2. Cellular and developmental science 3. Neuroscience and mental health. 4. Infection and immune-biology. 5. Physiology 6. Population health 7. This includes a broad sweep of conditions.
Identified research priorities	As above
Commissioned research?	Response mode funder for research within the areas they support.
How funding decisions are made	Do applications include any lay documentation?: 1. Most applications require a lay summary which should include key research goals and be targeted towards a non-expert audience. Are lay members involved in reviewing grant applications?: 1. No. Funding decisions are made via expert peer review panels
Are separate PPIE funds available	Yes, they have a specific Fund for PPIE. This can be applied for as part of the original project funding or as a stand-alone fund. Applicants can apply for funding for anything from £5000 to £3 million. link
Reference to public priority setting	No mention on website