NIHR | Research Design Service East of England

Inclusive Involvement in Research Showcase

What the RDS can offer

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CHSCR Centre for Health Services and Clinical Research

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NIHR | National Institute for Health Research

It funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth.
NIHR is the nation’s largest funder of health and care research, spending £1 billion from the Department of Health and Social Care on research every year.

https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-learn-about-research/how-we-fund-research.htm
https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-learn-about-research/

https://bepartofresearch.nihr.ac.uk/

Patient and public involvement (PPI), service user involvement, lay involvement or consumer involvement

Involvement in research = active partnership between members of the public and researchers… members of the public work alongside the research team and are actively involved in contributing to the research process as advisers and possibly as co-researchers, that is different from **co-production**

Engagement = information and knowledge about research is provided and disseminated to or by the public.

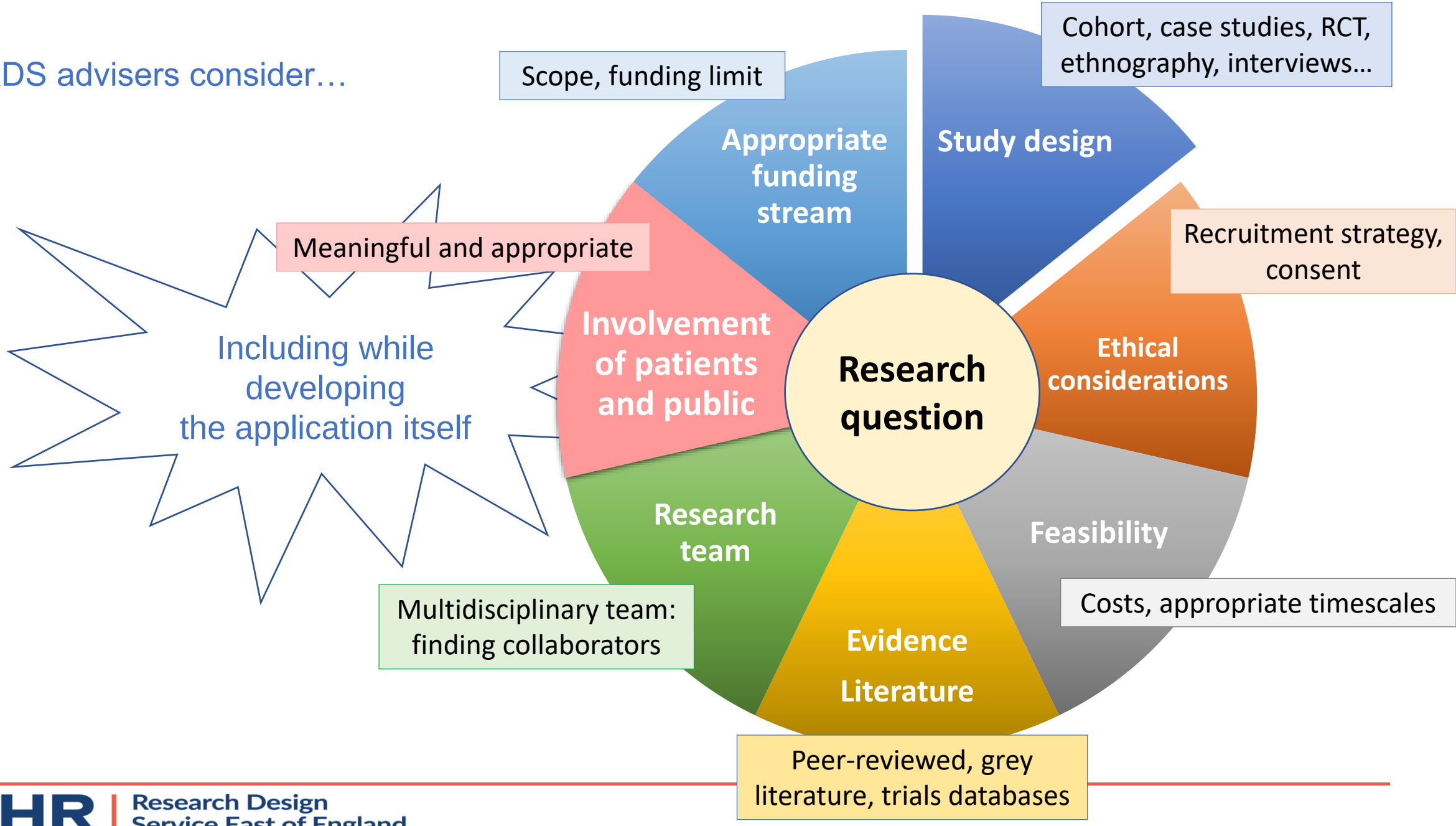
Participation refers to the process of people taking part in the research study.

These activities are different but are also linked and complement each other.

https://bepartofresearch.nihr.ac.uk/ https://www.rds-sc.nihr.ac.uk/information-for-researchers/#

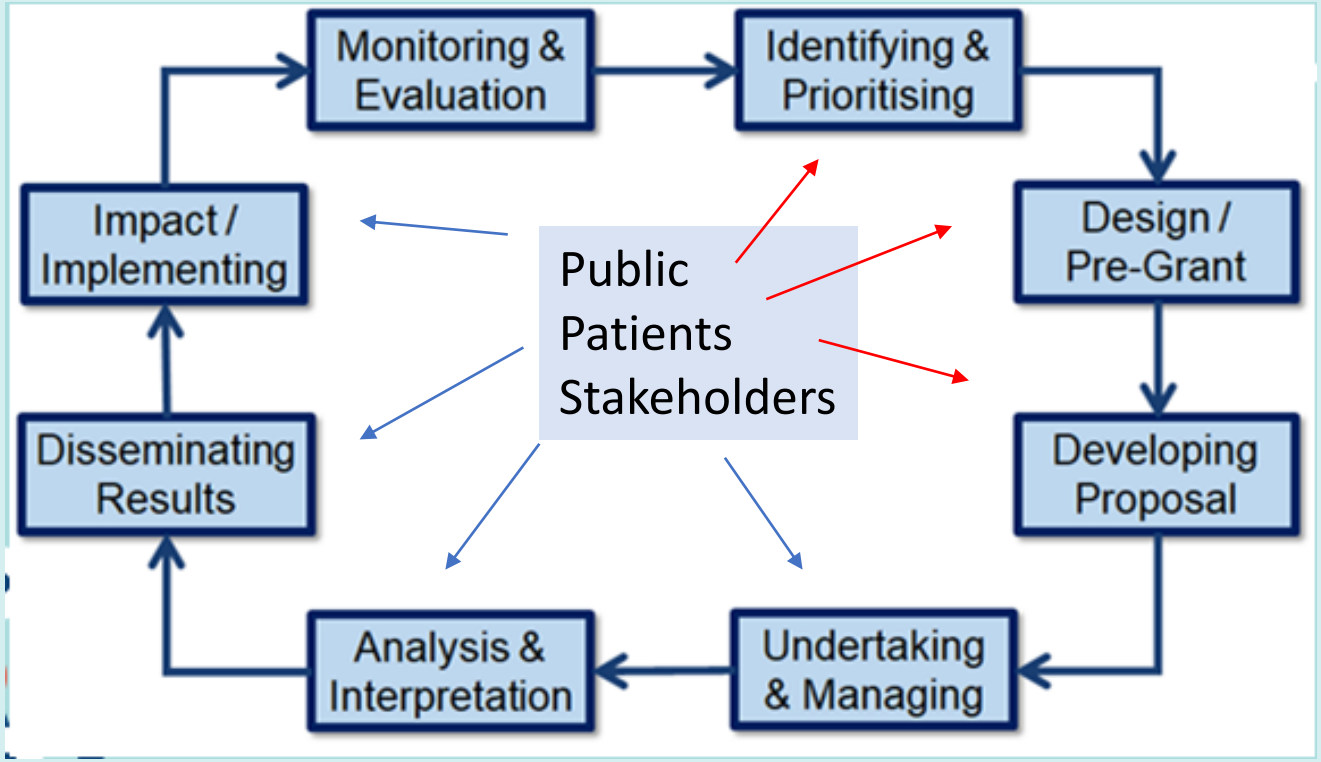
Standards for Public Involvement in Research: https://sites.google.com/nihr.ac.uk/pi-standards/home

RDS advisers consider…



What is a research grant application?

A **sales pitch**, an application for money aimed at
Convincing a funder that your **idea** is important,
You and your team are **expert** enough and
your **approach** is good to deliver something **meaningful** to them and the public and they will get **Good value for money**



Some things I look for in an application.

- Clear roles.
- Diversity
- Reflects the National Institute Health Research (NIHR) Patient Public Involvement (PPI) standards
- Worthwhile question with sensible measures
- Patient benefit
- Plain English summary is plain English and easy to understand.
- Burden on participants
- Evidenced involvement so far.
- Learning and development opportunities and necessary support to allow real involvement.
- Budget – if it is not in the budget it won't happen. Too low budget.
- A gut feeling? Sometimes it just doesn't seem right.

Thanks to Amander Wellings, Public Co Applicant and Panel Member

GOOD PPIE PRACTICE

- Involve members of the public as early as possible
- Discuss with them what skills and experience they have, how they may wish to be involved and their training/support needs
- Ensure that your research intention is clear for those outside your professional specialty who may be reviewing your application

How RDS can help

- We offer advice and support at early stage to help facilitate the process and introduce you to relevant people

Public Involvement groups and networks

https://rds-eoe.nihr.ac.uk/public-involvement/public-involvement-groups-and-networks/

Guidance and resources

https://rds-eoe.nihr.ac.uk/public-involvement/public-involvement-resources/

Training opportunities

https://cambridgebrc.nihr.ac.uk/public/online-ppi-events-training/

How RDS can help - continue -

- We assess application and check that public involvement is embedded throughout the project, e.g.

  Relevance of topic; Selection of suitable outcome measures;
  Feasibility; Development of study materials; Dissemination of results

- We encourage to engage with a **diverse community** on projects

  > planning research in the community, and with the community the research seeks to benefit.

- We advise on how to involve members of the public in research and how to budget for public involvement

  - Panel members provide public insight at our review panels and workshops including Bid Development Workshops, Pre-Submission Panels and Mock Interviews for NIHR Fellowship or i4i.

Public Involvement During COVID-19, tips and links:

https://rds-eoe.nihr.ac.uk/public-involvement/public-involvement-during-covid-19/

RDS EoE Public Involvement Fund

This fund is available to researchers to support early public involvement activities in advance of their funding application.

Essentially, a maximum of **£300** can cover **travel expenses, room hire, catering and also payment for a volunteer's time.**

The researcher needs to contact the Finance department of their employer (host institution) as they will be raising the invoice (to UoE). The researcher will also need to contact their Human Resources department for policies and processes for managing such payments.

The lead adviser must read and sign the application.

https://rds-eoe.nihr.ac.uk/rds-ssl-2019/wp-content/uploads/2021/11/RDS-EoE-Public-Involvement-Fund-Application-Form_2021_09_01.docx

Remember to feedback participants!

https://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf

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The quality of plain English summaries

Readability tools:

Hemingway Editor App

The Writer readability checker

INVOLVE review and guidance of importance of PES - 2013
> NIHR Centre for Engagement and Dissemination – CED 2021

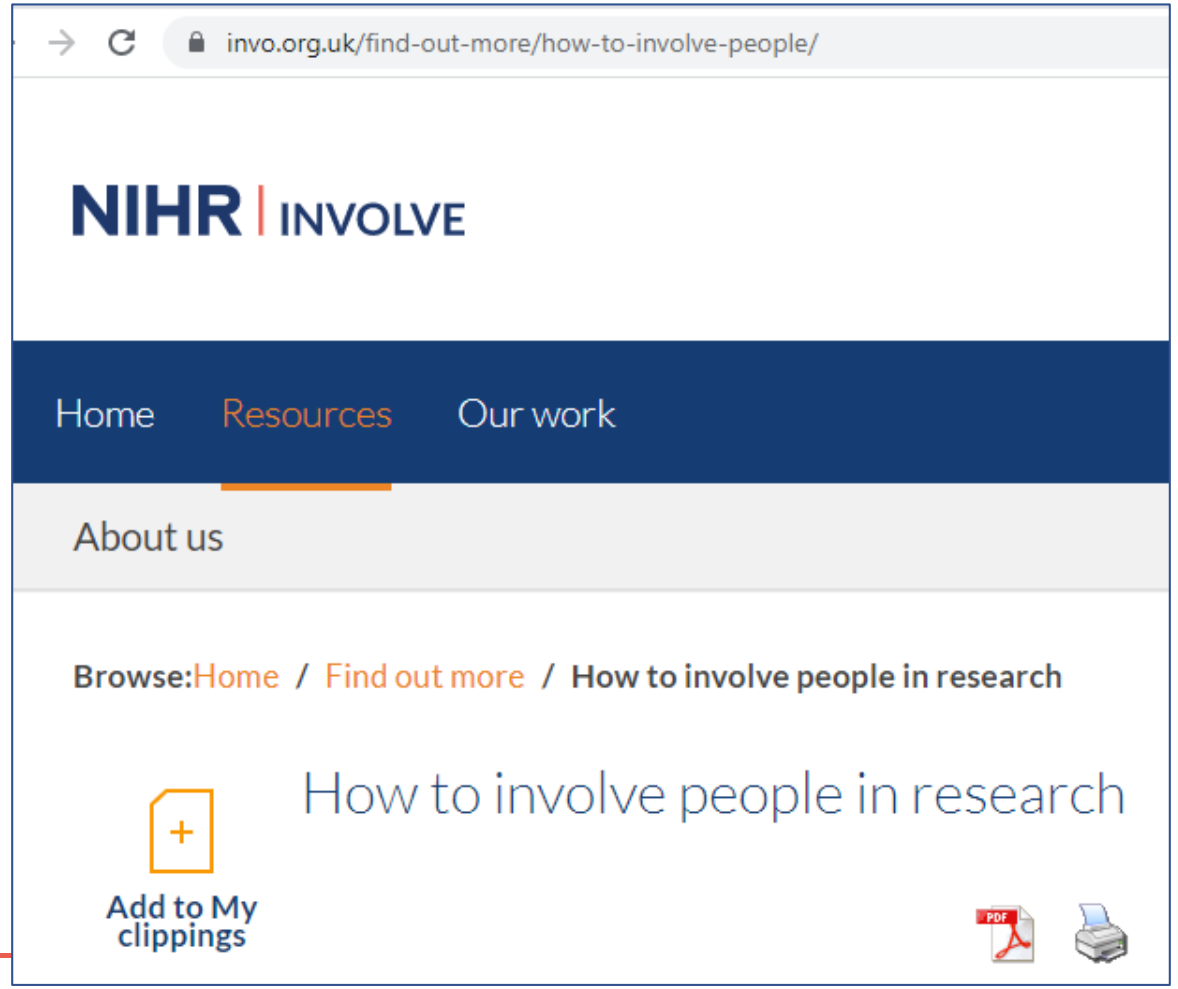
https://www.nihr.ac.uk/documents/plain-english-summaries/27363

- The aims of the plain English summary (PES)
  - To assist with reviewing applications and
  - To provide a publicly available, stand alone summary of the research

- The plain English abstracts of successful applicants are all made publicly available on programmes' websites – NIHR and charities included

  > should be updated and checked by applicants

- Producing a high quality summary is a requirement for funding



The poor plain English summaries

- Too short
- Overly-simplistic to the point of being condescending
- Unintelligible*
- Repetitive - copying other parts of the form
- A public relations exercise – over-selling the importance of the research

* avoid using jargon and technical terms – explain them clearly

› avoid complicated English or uncommon words

› use active not passive phrases

› keep sentences short, use bullet lists

› **ask patients / carers / colleagues to read a draft**

A good quality plain English summary:

- is written clearly in plain English
- has a logical structure and flows
- is pitched at the right level
- provides a detailed case for support
- addresses the issues of interest to patients / the public
- should include brief information on public involvement in the research
- patients / the public should be involved in developing / commenting on

NIHR standard application form – summaries guidance

(revised but strikethroughs are still relevant for project plan)

- Aim of the research
  - What are you aiming to find out?
  - How will patients / carers / members of the public and the NHS benefit from your research – either directly or in the longer term?
- Background to the research
  - Why does this research need to be done now?
  - How many patients / members of the public are affected and / or what are the costs to the NHS and other related services? >>> scale of the issue
- Design and methods used
  - What design and methods have you chosen and why? (in brief)
- Who are your participants (if included)
  - ~~How do you know taking part in your research will be acceptable to them?~~
  - ~~How will you ensure that you can recruit sufficient numbers?~~
- Patient and public involvement
  - How have patients / the public been involved in developing this research to date?
  - How will patients / the public be involved in the conduct / management of the research?
- Dissemination
  - How will the findings be communicated and to whom?
  - ~~How will you seek to influence practice?~~ >>> Impact

Examples from plain English summaries

Jargon

- ACRONYMS
- Efficacy of X – how well X works
- Probability – how likely X is to happen … 1 in 20 / 1 in 50 … (avoid %)
- Participate in – take part
- Prior to – before
- Discontinue – stop
- In the event of – if
- Inform – tell
- Scheduled to undergo – due to have
- Accordingly, consequently – so
- Utilisation – using
- With reference to, with regard to – about
- If this is the case – if so

- Additional - extra
- Applicant - you
- Commence - start
- Consequently - so
- In respect of - for
- Per annum - a year
- Prior to - before
- Intervention/Procedure (avoid it)

Aim: reducing complexity of written language

- Written for a reading level of 9-11 year old

Participants will be recruited by the research team at the xxx who have a strong track record of conducting large-scale studies of a similar nature

… it becomes: *We will recruit participants…*

or

frequently diagnosed at an advanced stage >>> when is too late
and often associated with poor outcomes >>> patients do not recover properly
post-surgery outcome >>> how a patient reacts after surgery

- Include input of PPI members

Our public team members who had xy told us this is acceptable

- Do not cut-and-paste your scientific abstract

Good quality examples of an easy to read overview

Background

Type 2 diabetes is a common health condition that can cause serious health problems and reduce people's quality of life, as well as costing a lot of money to treat.

Some people are at higher risk of diabetes, and can be identified with a blood test. If people at risk make changes to their lifestyle (more exercise, losing weight), they can substantially reduce their chances of getting type 2 diabetes.

The NHS and Diabetes UK are introducing a new scheme called Healthier You: the NHS Diabetes Prevention Programme (NHS DPP). People in England who are at risk of type 2 diabetes will be offered a practical course which will help them change their lifestyle. The aim is that this course will improve peoples' health and reduce their diabetes risk.

The people introducing the NHS DPP need to know if it really works to prevent diabetes and whether it is a good use of NHS resources. We have designed a project which will help answer these questions.

https://www.nihr.ac.uk/documents/hsanddr-programme-application-plain-english-summaries/19917

continue…

Research plan

We will look at data from the NHS DPP and from other sources, to see what types of patients are invited onto the course. We will also talk to patients and NHS professionals to understand how people are invited, and whether different ways of inviting people help or hinder certain people from attending.

We will use this data to see if the NHS DPP is being used by those who need it most.

We will talk to NHS clinical staff and managers responsible for the NHS DPP programme throughout England. We will ask them how they set up the service, what issues they believe help and hinder the programme, and whether they consulted with patients and their carers.

We will watch as the NHS DPP is delivered to patients at risk of diabetes. We will check to see if it is done well, and what might be improved. We will look at data collected by the NHS DPP to see if registered patients finish the course and show good outcomes, such as healthy levels of blood sugar, feeling more confident about their health and losing weight.

We will make sure we feed all this information back to the people running the NHS DPP so they can make improvements as they go along.

The biggest challenge we face is testing whether this new NHS DPP is better at preventing type 2 diabetes than what the NHS currently does, and whether it is a good use of scarce NHS funds. To test this, we will use data that the NHS already collects in GP medical records. First, we will see if there are fewer cases of diabetes in these records after the NHS DPP is introduced, compared to the number of cases before. Then we will compare patients who were offered the course…

What is the question and hypothesis(es) related to multiple sclerosis that you are addressing with this project?

Example 1 – Basic Science

Diagnosis and treatment of MS remain challenging, in part because there is no single laboratory test that can identify whether a person has MS, or predict a person's expected disease activity in the future. Researchers have been working to identify "biomarkers," or biological signals, that could serve as indicators or predictors of MS. Myeloperoxidase (MPO) is a protein found in large amounts in MS lesions and contributes to tissue damage. We hypothesize that MPO promotes active disease in MS by causing damage to the nervous system…

Example 2 – Rehabilitation

Many people with MS may eventually experience difficulty with walking. The term "gait" refers more specifically to the manner or pattern of walking (for example "unsteady gait"). Studies suggest that half the people with relapsing-remitting MS will need some assistance with walking within 15 years of their diagnosis. Gait problems in MS are caused by a variety of factors. MS frequently causes fatigue, which can limit walking endurance. MS damage to nerve pathways may hamper coordination and/or cause weakness, poor balance, numbness, or spasticity (abnormal tightness of muscles). …

National Multiple Sclerosis Society's
https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Research/Examples_of_Plain_Language_Summaries.pdf

What is the question and hypothesis(es) related to multiple sclerosis that you are addressing with this project?

Example 3 – Epidemiology

Multiple Sclerosis (MS) is a common immune-mediated disorder that involves immune attacks and inflammation in the brain and spinal cord (collectively they comprise the central nervous system). The cause of MS remains subject to intense investigation. Many common genes have been linked to susceptibility to MS, but carrying MS-linked genes alone does not mean a person will develop MS. Other factors, such as lifestyle and environmental factors, are also thought to play a triggering role. Exposure to air pollution (an environmental factor) has been implicated in a wide variety of diseases, such as heart disease and stroke, and it is thought to cause inflammation and other negative effects in the body. However, the effects of air pollution on diseases of the central nervous system have not been thoroughly explored. …

National Multiple Sclerosis Society's
https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Research/Examples_of_Plain_Language_Summaries.pdf

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https://rds-eoe.nihr.ac.uk/contact-us/client-enquiry-form/