

Health Data in Practice lecture series

Co-production in research

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1st December 2020



Learning Objectives

At the end of this lecture on co-production you will be able to:

- Understand co-production and associated methods
- Understand why researchers and the public might undertake co-production
- Think creatively about the range of options for involving the public in research
- Have a practical understanding of how to go about co-producing research, drawing on key examples
- Summarise the challenges associated with co-production
- Access key readings and the assignment

‘Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.’

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Defining co-production and public involvement

- Linked terms: community based participatory research, co-design, co-production, patient or public involvement, co-researchers, citizen science, user involvement, action research, street science, public engagement
- There are blurry boundaries between these terms
- All are distinct from participation in research, where members of the public are research subjects, as part of focus groups, RCTs etc.



Ladder of involvement



Types of involvement



User-led/
controlled

Collaborative

Consultation

Public engagement

- Where information and knowledge about research is provided and disseminated

"Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit"

- The National Co-ordinating Centre for Public Engagement (NCCPE)

- 1. Informing/Inspiring:** informing, inspiring and educating the public, making your work more accessible and understandable
- 2. Consulting:** actively listening to the public's concerns and insights
- 3. Collaborating:** working in partnership with the public to solve problems together, drawing on each other's expertise

Going Beyond Involvement: Principles of Co-production

No one size fits all method, coproduction is guided by key principles:

- Sharing of power – *the research is jointly owned and people work together to achieve a joint understanding*
- Including all perspectives and skills – *make sure the research team includes all those who can make a contribution*
- Respecting and valuing the knowledge of all those working together on the research – *everyone is of equal importance*
- Reciprocity – *everybody benefits from working together*
- Building and maintaining relationships – *an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.*



https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf



ANY QUESTIONS?





“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”



Professor Dame Sally Davies, CMO



Why should researchers co-produce research?

Normative / emancipatory

Members of the public have a right to be involved in research that might affect them and can reduce power imbalances between researchers and public

Consequentialist / efficiency-oriented

Bringing a lived experience and real-world perspective contributes to improving the efficiency and value of research

Political / practical

Co-construction of knowledge through alliances between researchers and patients can increase research accountability and transparency

- Also – often a requirement for funding and publishing your research



To ensure research is:



Instrumental impact

Influencing the development of policy, practice or service provision, shaping legislation, altering behaviour



Conceptual impact

Contributing to the understanding of policy issues, reframing debates



Capacity building impact

Through technical and personal skill development

Ethical and fair?



Feasible?

Impactful?



Attitudinal or cultural impact

e.g., increased willingness in general to engage in new collaborations



Lasting connectivity impact

e.g., follow-on interactions: joint proposals, visits, shared workshops

Relevant?



Why do the public get involved in research?

- Wanting to help others, and contribute to a better healthcare system
- Wanting patient perspectives to be reflected and have influence in research and ultimately on healthcare
- Interest in research and in contributing to scientific knowledge
- Interest in the healthcare topic, often because of personal experience



THIS Institute report - Involving patients and the public in research



ANY QUESTIONS?



*“As healthcare professionals we mustn’t
assume we know more than anyone else does!
You have to recognise that other people are
experts and accept that other people have skills
that will make your project work.”’*

Swithenbank 2010

How to get started?

Start early so people have ownership of the project

Explain why you want people to be involved

Be prepared to share key decisions

Consider impact from the beginning



Communicate clearly and ask people if they need support to be involved

Set clear expectations about roles, time demands and what people will get out of being involved

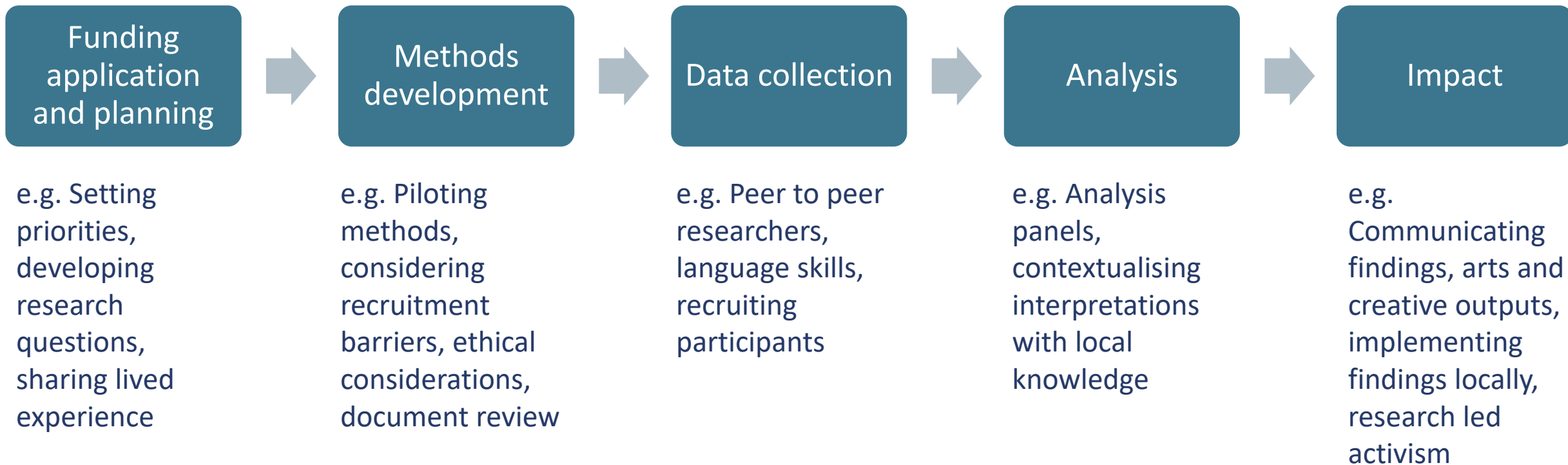
Reflect on progress and record everything

Be clear about what aspects of the project can be influenced, and what is fixed

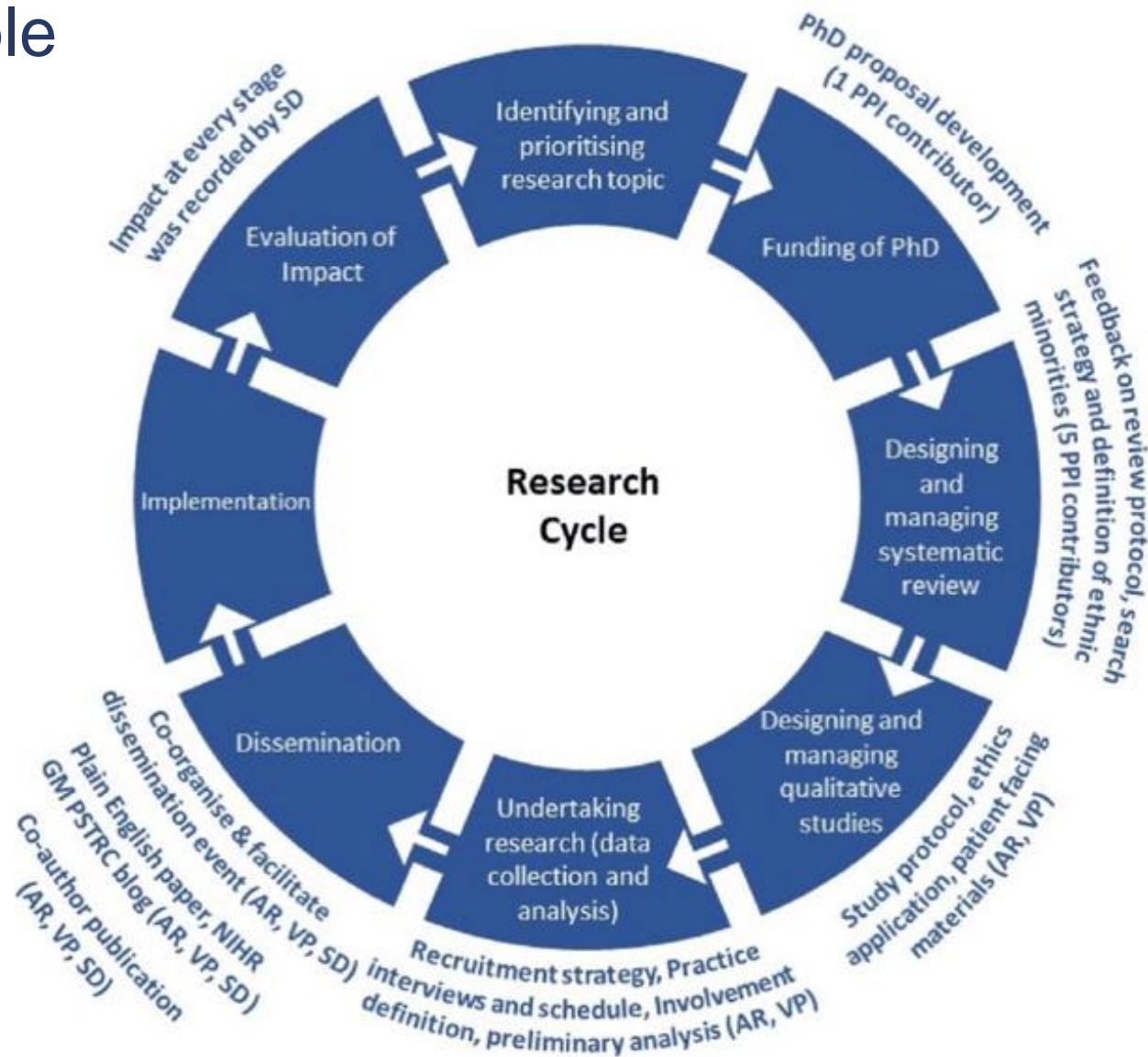
NIHR INVOLVE Briefing notes for researchers

How to get started?

- Think about every stage of the research project:



PhD Example



Dawson et al. Patient and public involvement in doctoral research: reflections and experiences of the PPI contributors and researcher. *Research Involvement and Engagement* (2020) 6:23

Identifying co-researchers

Finding PPI Representatives:

- People in Research
- Social media
- NHS clinical commissioning groups
- NHS trusts
- Universities
- Charities
- Flyers in local community spaces



Think about your research context and be compliant with GDPR

Consider who has a voice, and who is being silenced

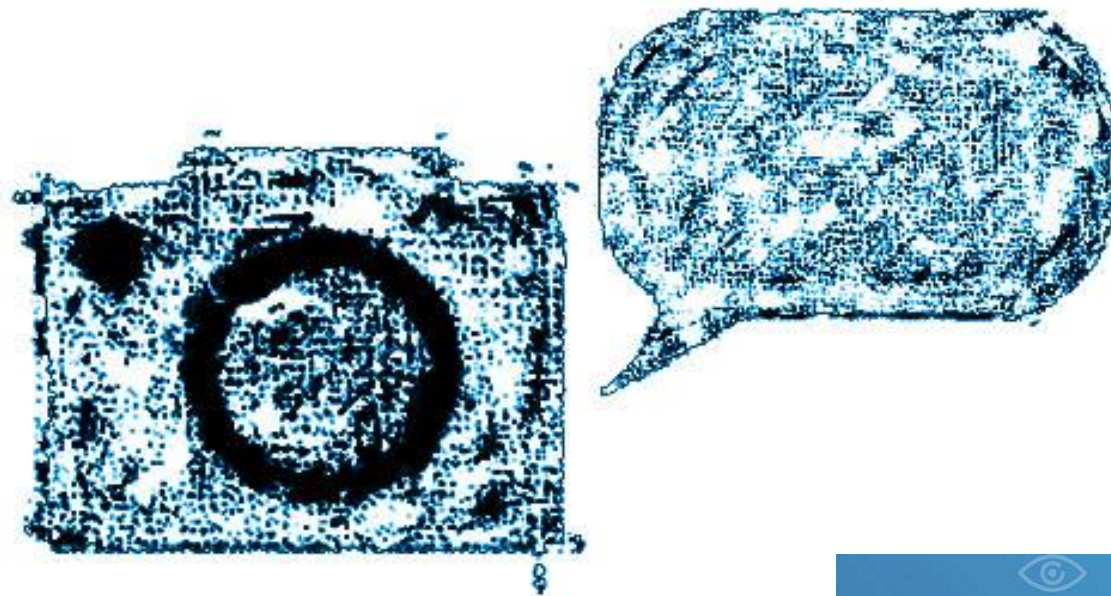
Research Advisory Panels



Virtual methods



Online workshops e.g. zoom/ skype



Creative methods e.g. photovoice, video diaries, arts and writing

Telephone interviews



Message boards, online communities, email review



Things to consider

Does it facilitate equal access?

Have I budgeted costs appropriately?

Is the group representative of the research population?

How am I giving back? Is it reciprocal?

Am I respecting different forms of knowledge equally?

Who has the power? How can I address this?

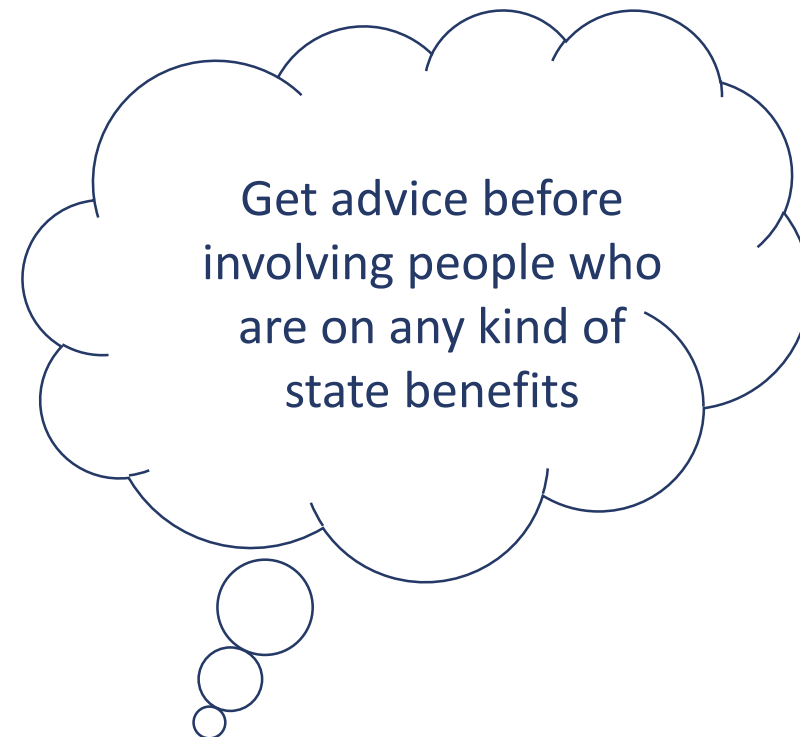
Will it remain confidential and safe? Am I putting anyone at risk?

Is this the best way for people to share?

Have I considered language and communication?

Setting a budget

- travel and subsistence expenses
- childcare and carer costs
- costs for personal assistants
- payment for time and work undertaken
- hire of accessible venues
- additional support such as an independent facilitator
- refreshment costs
- hotel accommodation costs
- translation and interpretation costs
- training and support
- administrative support
- telephone, photocopying and postage



NIHR INVOLVE Briefing notes for researchers

Reporting and Impact

- Think about impact from the beginning – how will you evaluate the impact of co-production on your project, as well as the project itself
- Reflect on how coproduction has shaped your findings
- Record as you go along
- Follow GRIPP2 reporting guidelines
- Add details to the research project database on the INVOLVE website
- Acknowledge work fairly
- Include information on coproduction process in all research publications
- Think outside the box when it comes to impact!

RESEARCH METHODS AND REPORTING

OPEN ACCESS

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

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Additional material is published online only. To view please visit the journal online.
Cite this as: *BMJ* 2017;358:j3453
<http://dx.doi.org/10.1136/bmj.j3453>

GRIPP2 (short form and long form) is the first international guidance for reporting of patient and public involvement in health and social care research. This paper describes the development of the GRIPP2 reporting checklists, which aim to improve the quality, transparency, and consistency of the international patient and public involvement (PPI) evidence base, to ensure that PPI practice is based on the best evidence and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2.

METHODS
The EQUATOR method for developing reporting guidelines was used. The original GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklist was revised, based on updated systematic review evidence. A three round Delphi survey was used to develop consensus on items to be included in the guideline. A subsequent face-to-face meeting produced agreement on items not reaching consensus during the Delphi process.

RESULTS
143 participants agreed to participate in round one, with an 86% (123/143) response for round two and a 78% (112/143) response for round three. The Delphi survey identified the need for long form (LF) and short form (SF) versions. GRIPP2-LF includes 34 items on aims, definitions, concepts and theory, methods, stages and nature of involvement, context, capture or measurement of impact, outcomes, economic assessment, and reflections and is suitable for studies where the main focus is PPI. GRIPP2-SF includes five items on aims, methods, results, outcomes, and critical perspective and is suitable for

ABSTRACT
BACKGROUND
While the patient and public involvement (PPI) evidence base has expanded over the past decade, the quality of reporting within papers is often inconsistent, limiting our understanding of how it works, in what context, for whom, and why.
OBJECTIVE
To develop international consensus on the key

BMJ: first published as 10.1136/bmj.j3453 on 2 August 2017. Downloaded from <http://www.bmj.com/>

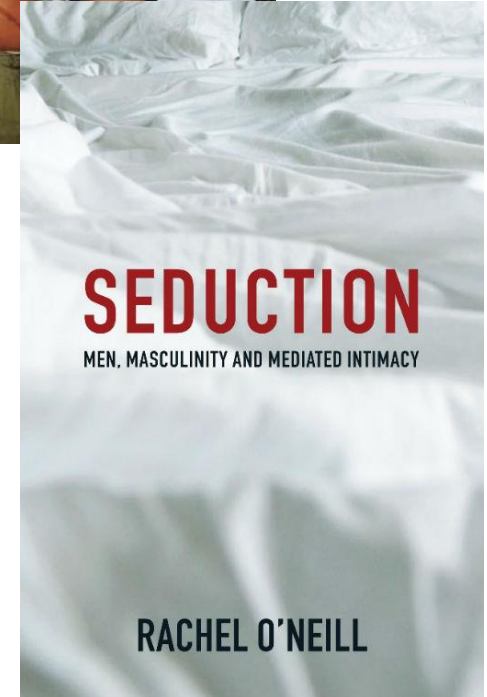
<https://www.bmj.com/content/bmj/358/bmj.j3453.full.pdf>
www.involve.nihr.ac.uk/resource-centre/research-project-database

Discussion: Challenges

- Funding and valuing the 'work' in academia
- Maintaining relationships over time
- Tokenism
- Equality of access - Accessing seldom accessed groups (COVID-19)
- Communicating well
- Genuine reciprocity
- Differing priorities/ viewpoints
- Constraints in the system (e.g. paying people)
- Confidentiality / ethical considerations (GDPR)
- Undertaking critical or 'guerrilla' research



Nancy Scheper-Hughes





ANY QUESTIONS?



Example 1: The Nurture Early for Optimal Nutrition (NEON) project



A multi-phase project that aims to optimise feeding, care and dental hygiene practices in South Asian children <2 in East London using participatory learning and action cycles facilitated by a multi-lingual community facilitator.

Lakhanpaul 2020

<https://www.ucl.ac.uk/child-health/research/population-policy-and-practice-research-and-teaching-department/champp-child-and-6>

Example 2: CLARHC North Thames RAP

NIHR | Collaboration for Leadership
In Applied Health Research
and Care North Thames



<https://clahrc-norththames.nihr.ac.uk/celebrating-patient-and-public-involvement-in-our-research/>



 Queen Mary
University of London
Barts and The London



qmul.ac.uk/healthdatadtp



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Further reading and Assignment

- Key readings will be posted on QMPlus
- Slides will be available on QMPlus

Assignment – 20% of Module Grade

- Read key research paper: Sharpe et al 2018 *'It's my diabetes': Co-production in practice with young people in delivering a 'perfect' care pathway for diabetes.*

Part 1: Provide a lay summary of the paper (500 words) including the key findings.

Part 2: Give an overview of the strengths and limitations of their approach (250 words) and your suggestions for how they could improve their approach in the future (250 words).

Deadline: **15th December**