

Patient and Public Involvement (PPI) in Research

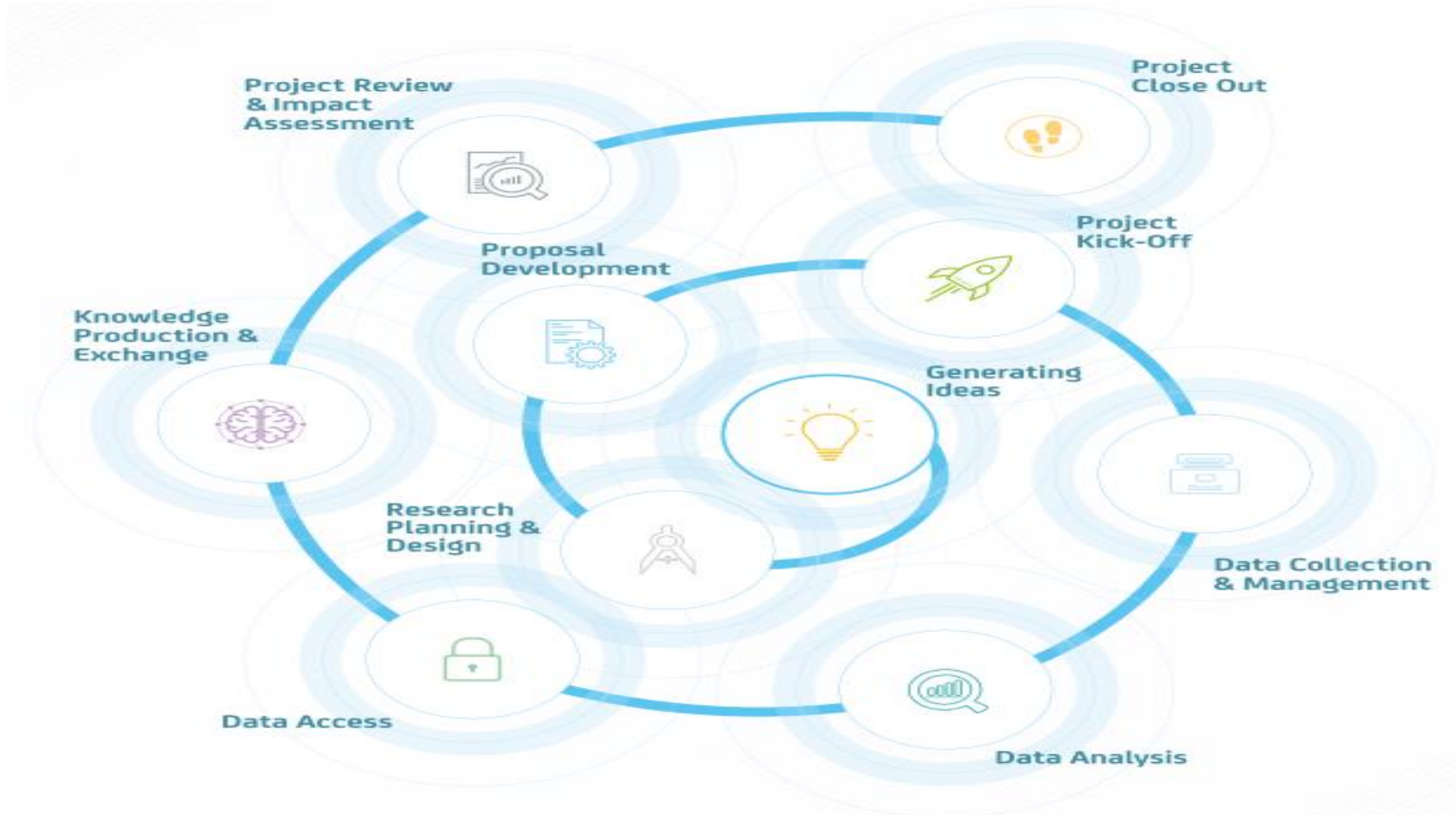


Lucy Whiston
Research Fellow
DCU PPI Ignite
School of Nursing, Psychotherapy and
Community Health

Objectives

- Identify public and patient involvement (PPI) in research
- Understand the benefits and challenges of PPI in research
- Develop a plan for PPI in your own research
- Locate resources and supports for PPI in research

The research process (1)



What is PPI?

PPI is 'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them' (2).

Who

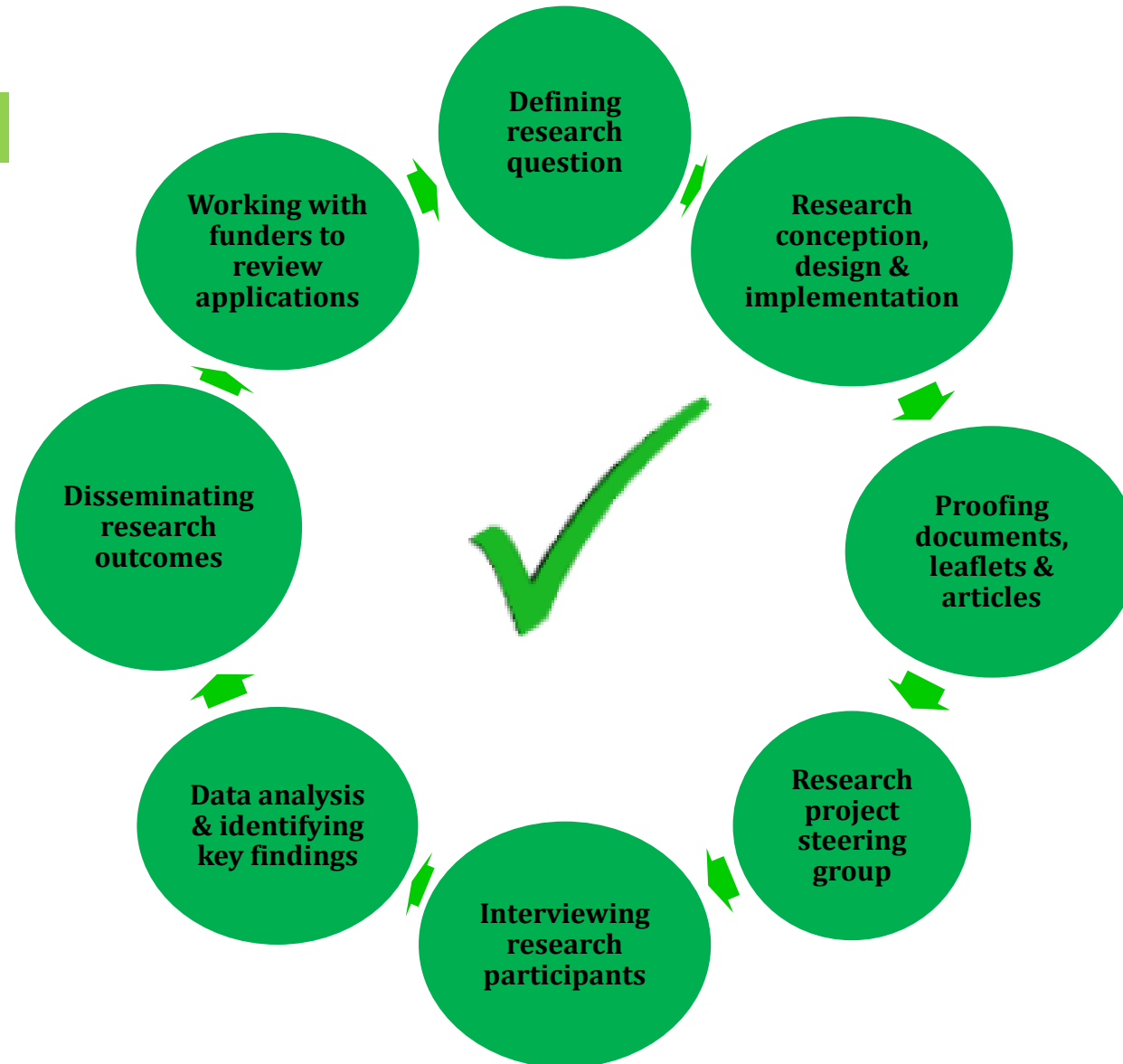
- Those whom the research will impact or affect

What

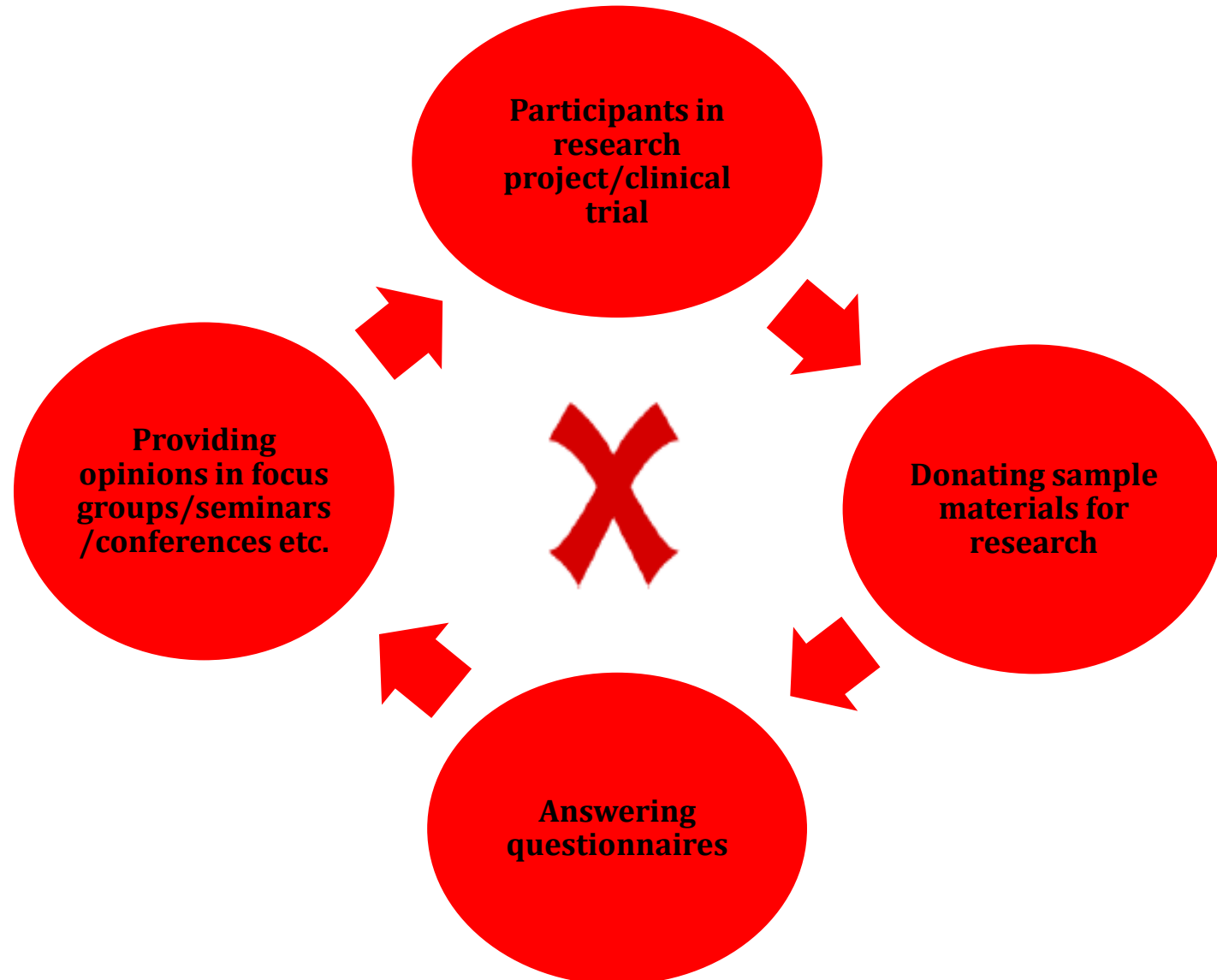
- Engagement X
- Participation X
- Involvement ✓

PPI is..... Public/patients as active partners

Involved in...



PPI is not..... Public/patients as data providers

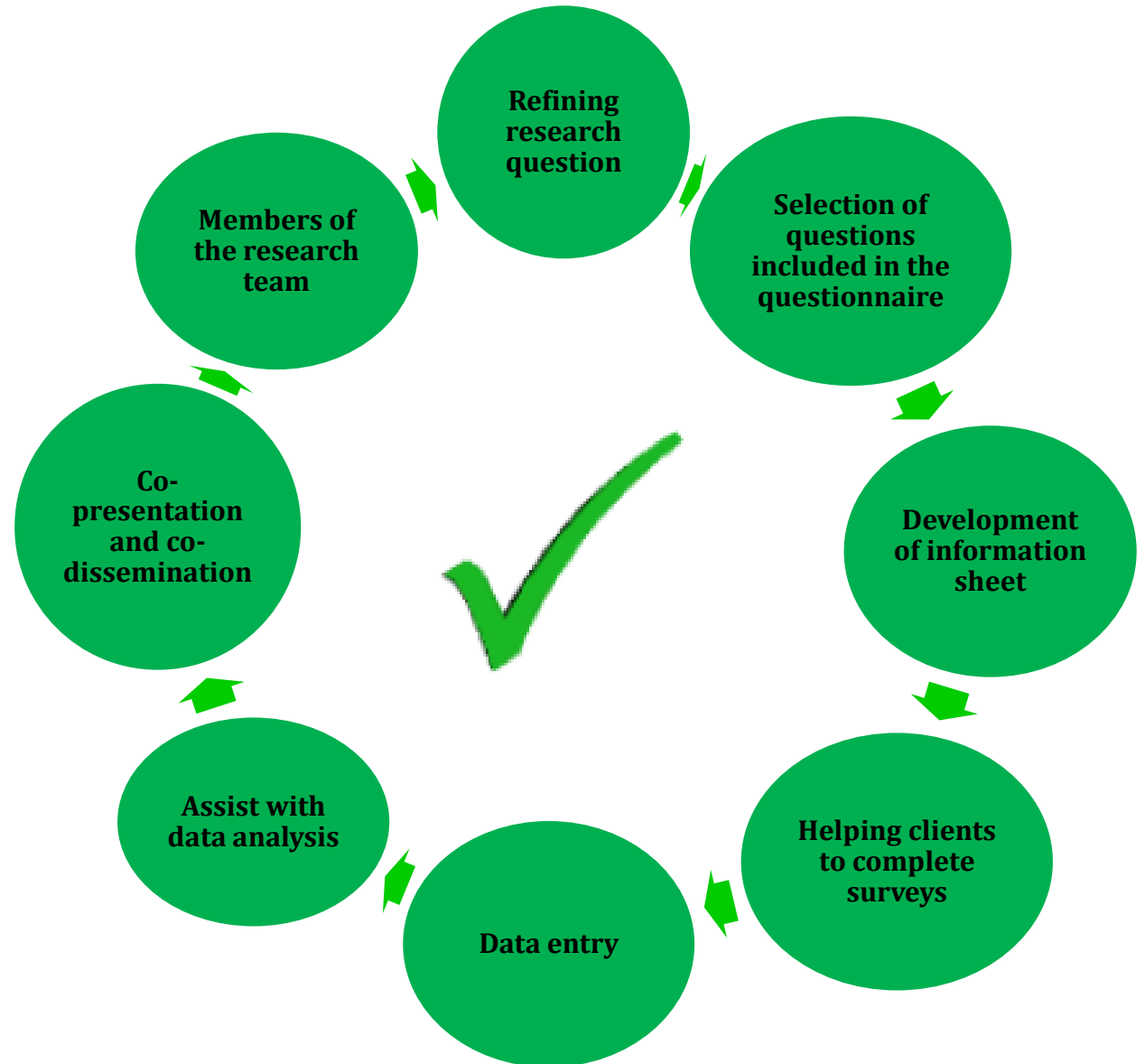


PPI Example

Project:

Dublin Simon
Community
Service User Led
Evaluation

Method: Peer
researcher
administered
questionnaires



Terminology- patients and the public^(3,4)

Patients

Consumers

Service users

Customers

Diabetic

People

People living with ...

Lay people

Public

Members of the general public

Citizens

Experts by experience

Advocates

PPI contributors

Patient organisations

Support groups

Charities for people with ...

Family members

Carers

Caregivers



Terminology- involvement (2)

Involvement: where people are *actively* involved in research projects and research organisations

Participation: where people take part in a research study

Engagement: where information and knowledge about research is shared with the public

Importance of PPI

Growth and interest

-14% increase in reported PPI 2007-2010 (5)

Moral/ethical arguments

More credible, higher quality research (5-9)

- More appropriate and relevant research
- Improvements in recruitment
- More user friendly data collection
- Enhanced implementation and dissemination

Importance of PPI

Research and funding body support

- Aided researchers in securing funding (10)
- Cochrane Colloquium 2018 a Patients Included event
- European Commission (Horizon 2020)
- British Medical Journal
- IRC
- HRB

Barriers to PPI

Time

- 66.7% (18/27) of researchers
- *‘A lot of our member have complained about the last minute call of “We are submitting a grant application in two days time...Do you have patients who can play these roles?”’ (Mary)*

Implementation

- Funding 59.3% (16/27) of researchers
- Recruitment 59.3% (16/27) of researchers
- *‘Payment is one thing and I know how tricky and complex that is... in some research projects it might be difficult to pay people and then in others there are issues with welfare payments and all sorts. That is a barrier.’(Vincent)*

Enablers to PPI

Researchers

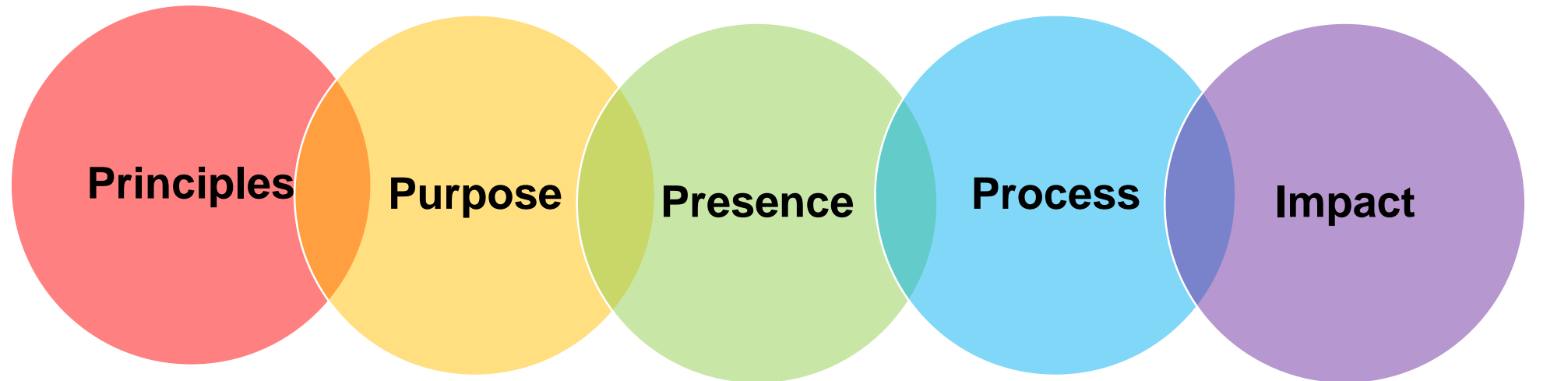
- Accessible patients and public 74.1% (20/27)
- Links with organisations 70.3% (19/27)
- Positive impacts on research 70.3% (19/27)

Patient organisations

- Support for PPI
- *‘Most patient organisations are on side with this...there is a great hunger among patients and families’ (Howard)*
- *‘The PPI Ignite is a really, really strong enabler’ (Mary).*

What to think about

4Pi National Standards for involvement ⁽¹¹⁾



Principles

Purpose

Presence

Process

Impact

- Equality
- Fairness
- Respect
- Inclusivity

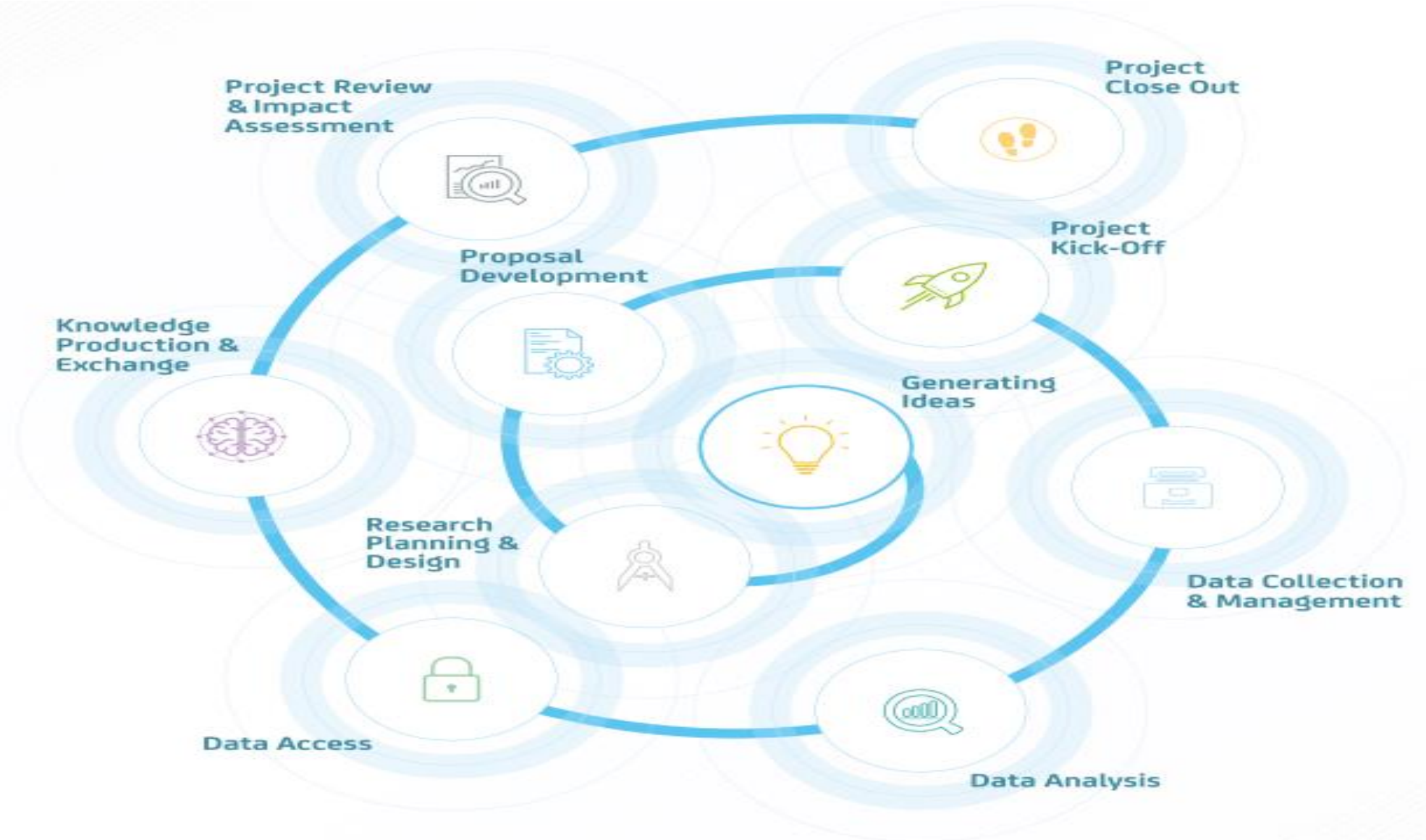
- Why
- Outcomes
- Limits
- (2, 12-14)

- Who
- Role
- (2, 14, 15)

- How
- Supports
- (1, 16-19)

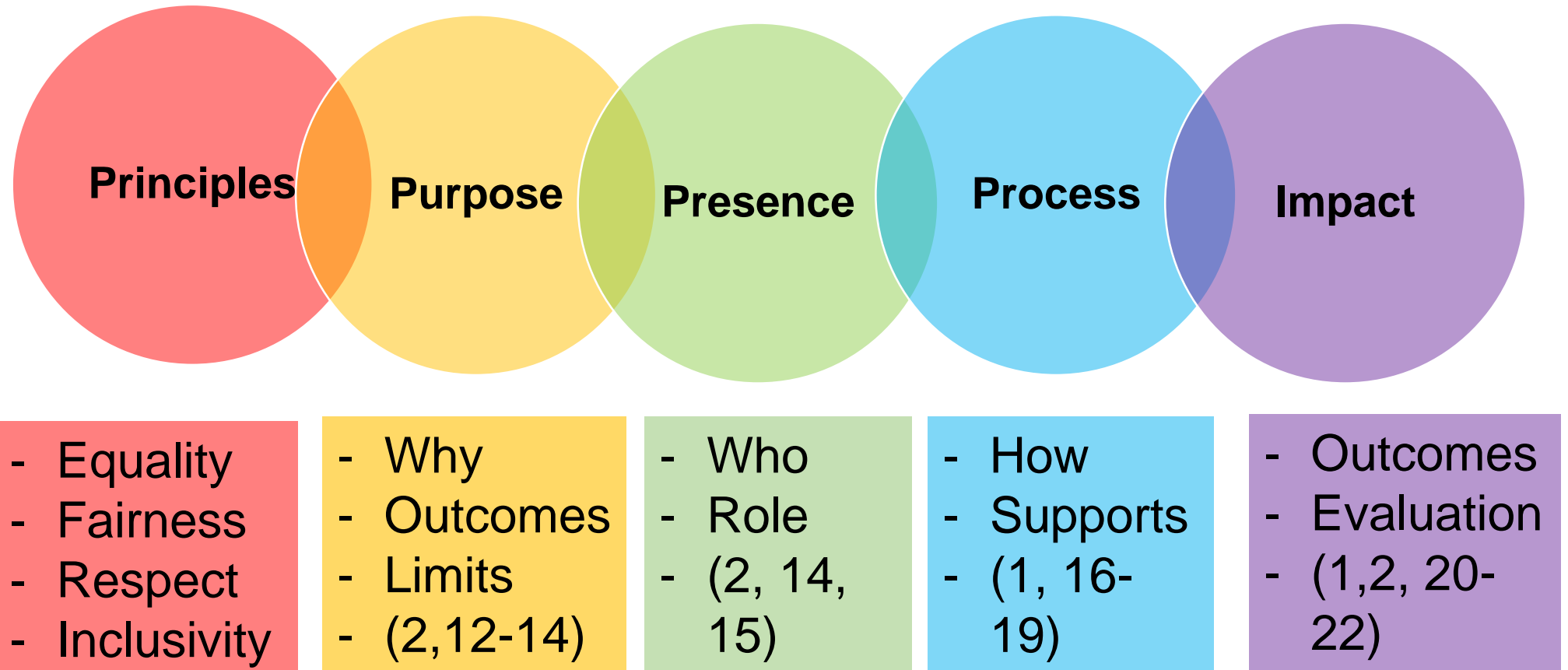
- Outcomes
- Evaluation
- (1, 2, 20-22)

What to think about- process (1)



What to think about

4Pi National Standards for involvement ⁽¹¹⁾



PPI Resources

- There is no 'one size fits all' approach
- Available resources (reference list)

PPI Ignite Awards

- Training
- Resources (<https://www.dcu.ie/ppi/resources.shtml>)
- Support and guidance
- Partner organisations

PPI Resources

DCU PPI Ignite PPI in Research Seminar Slides and Recordings (2018-2019 and 2019-2020)

- An introduction to PPI (DCU PPI Ignite)
- PPI in grant applications (HRB)
- Developing a PPI project (Liam MacGabhann and Brendan)
- Communicating with patients, the public and patient organisations (Avril Kennan, HRCI and Laura Brady, Fighting Blindness)
- The who, how, what and why of PPI (Gary Hickey, INVOLVE)
- Writing a lay abstract (Sean Driver, NALA)
- Budgeting for PPI (Lucy Whiston, DCU PPI Ignite)

<https://drive.google.com/open?>

[id=18uaF85_czQW6bfYNWxgWZSaMwa1lZqA6&authuser=lucy.whiston@dcu.ie&usp=drive_fs](https://drive.google.com/open?id=18uaF85_czQW6bfYNWxgWZSaMwa1lZqA6&authuser=lucy.whiston@dcu.ie&usp=drive_fs)

DCU PPI Ignite

[Home](#) [About](#) [Partners](#) [News and Events](#) [Resources and Supports +](#) [Contact Us +](#)

Resources

Some resources that might be helpful as an introduction to PPI in research are below.

An introduction to PPI

- Briefing notes for researchers: involving the public in NHS, public health and social care research
https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

- National Institute for Health Research. Patient and public involvement in health and social care research: A handbook for researchers by design services London

file:///C:/Users/whistonl/Downloads/RDS_PPI-Handbook_2018_WEB_VERSION.pdf

- NHS Health Research Authority Principles for PPI



Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

PPI Resources

- There is no 'one size fits all' approach
- Available resources (reference list)

PPI Ignite Awards

- Training
- Resources (<https://www.dcu.ie/ppi/resources.shtml>)
- Support and guidance
- Partner organisations

PPI Resources

Organisations

- INVOLVE
- NIHR
- NCCPE
- PCORI
- International PPI Network

Journals

- Health Expectations
- Research Involvement and Engagement



Questions?



Lucy.whiston@dcu.ie



[@PPI_Ignite_DCU](https://twitter.com/PPI_Ignite_DCU)

[dcu.ie/ppi](https://www.dcu.ie/ppi)



References

1. Bowman S, Morris K, Adshead M. A How To Guide: A Framework for Engaged Research- Society and higher education addressing grand societal challenges together [Internet]. Dublin, Ireland: Campus Engage, Irish Universities Association and Irish Research Council; 2018 [cited 2018 Jan 6]. Available from: <http://www.campusengage.ie/sites/default/files/resources/Framework%20for%20Engaged%20Research%20Web.pdf>
2. INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research [Internet]. Eastleigh: INVOLVE; 2012 [cited 2018 Jun 22]. Available from: http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
3. Kennan A. The language of patient and public involvement and how not to mess it up [Internet]. MRCG Blog. 2018 [cited 2018 May 11]. Available from: https://www.mrcg.ie/go/news/mrcg_blog
4. Morley R, Chapman S. What's in a name? Patients, people and the power of words [Internet]. Evidently Cochrane. 2017 [cited 2018 May 11]. Available from: <http://www.evidentlycochrane.net/patients-people-power-of-words/>
5. Vale CL, Thompson LC, Murphy C, Forcat S, Hanley B. Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey. *Trials* [Internet]. 2012 Jan 13;13(1):9. Available from: <https://doi.org/10.1186/1745-6215-13-9>
6. Ashcroft J, Wykes T, Taylor J, Crowther A, Szmukler G. Impact on the individual: what do patients and carers gain, lose and expect from being involved in research? *Journal of Mental Health*. 2015;1–8.
7. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC health services research*. 2014;14(1):89.

References

8. Hayes H, Buckland S, Tarpey M. Briefing Notes for Researchers: public involvement in NHS, public health and social care research [Internet]. Hampshire, England: INVOLVE; 2012 Feb [cited 2017 Dec 14]. Available from: http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
9. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expectations. 2012;
10. Health Research Board. Results of the Public and Patient Involvement Survey: How would you support public and patient involvement in research? [Internet]. Dublin, Ireland: Health Research Board; 2017. Available from: http://www.hrb.ie/fileadmin/Staging/Documents/RSF/Grant_Management_Nov_2015_onwards/2Pre_award_Grant_call_documents_/2016_grant_calls/Public_and_Patient_Involvement/HRB_PPI_survey_results.pdf
11. Faulkner A, Yiannoullou S, Kalathil J, Crepaz-Keay D, Singer F, James N, et al. 4PI National Involvement Standards: Involvement for Influence. England: National Involvement Partnership, National Survivor User Network; 2015 Mar.
12. Medical Research Charities Group. Developing a PPI Strategy: A Guide, Practical advice on developing a patient and public involvement (PPI) strategy for research activities. Dublin, Ireland: Medical Research Charities Group; 2018 p. 8.
13. NIHR. UK Standards for Public Involvement: Better public involvement for better health and social care research [Internet]. England: NIHR, Chief Scientist Office, Health and Care Research Wales, Public Health Agency; 2019 [cited 2019 Nov 27]. Available from: [file:///C:/Users/whistonl/Downloads/UK-Standards-for-Public-Involvement_Nov19%20\(1\).pdf](file:///C:/Users/whistonl/Downloads/UK-Standards-for-Public-Involvement_Nov19%20(1).pdf)
14. National Institute for Health Research. Patient and public involvement in health and social care research: A handbook for researchers [Internet]. National Institute for Health Research; 2014 [cited 2018 Jan 3]. Available from: <https://www.nihr.ac.uk/about-us/CCF/funding/how-we-can-help-you/RDS-PPI-Handbook-2014-v8-FINAL.pdf>
15. Vat LE, Ryan D, Etchegary H. Recruiting patients as partners in health research: a qualitative descriptive study. Research Involvement And Engagement [Internet]. 2017 Aug 21;3:15–15. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=29062540&site=ehost-live>



References

16. Cartwright J, Kabir T, Simons L. Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies. INVOLVE, National Institute for Health Research; 2013 Jun.
17. INVOLVE. Policy on payment of fees and expenses for members of the public actively involved with INVOLVE. INVOLVE, National Institute for Health Research; 2016 Feb.
18. Dcu Budgeting guidelines
https://drive.google.com/open?id=1uzGaydRCbkeGjYv3YGegL2KNYEY_pzRe&authuser=lucy.whiston@dcu.ie&usp=drive_fs
19. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. Health Expectations [Internet]. [cited 2019 Apr 23];0(0). Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.12888>
20. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ [Internet]. 2017;358. Available from: <http://www.bmj.com/content/bmj/358/bmj.j3453.full.pdf>
21. Boivin A, L'Espérance A, Gauvin F-P, Dumez V, Macaulay AC, Lehoux P, et al. Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. Health Expectations. 2018;21(6):1075–84.
22. Popay J, Collins M. PiiAF: The public Involvement Impact Assessment Framework Guidance. England; 2014 Jan.