



NATIONAL STANDARDS *for* PUBLIC INVOLVEMENT

Supported by the Standards Development Partnership



Foreword

I have yet to meet a person or group in public involvement that is not looking at ways of doing things better. It is one of the great strengths of our growing and vibrant movement in the UK and I suspect the reason why you are reading this booklet. Welcome.

This motivation to build upon the best, to learn from and share experiences with others, has been key to the evolution of these National Standards for Public Involvement. From their beginnings as a key recommendation in the NIHR report 'Going the Extra Mile,' up to and including the work that is now being done by 'Test Bed' organisations and others to pilot them. It will also be important to their long-term implementation and adoption.

In my view the Standards Development Partnership Group have succeeded in developing standards that support and encourage people to strive for the highest common aspiration in their public involvement. I hope that you will approach them in this spirit, using the Standards to open dialogue and stretch ambitions rather than limit horizons.

Partnership working and effective leadership has been fundamental to the Standards getting to this point and I would like to thank all those who have contributed to their development, in particular the members of the Partnership Group who have steered this project so effectively over the last two years.

I suspect that the same qualities have lead you and your colleagues to this handbook. On behalf of the National Institute for Health Research (NIHR), Chief Scientist's Office (CSO) Scotland, Health and Care Research Wales and the Public Health Agency Northern Ireland, I would therefore like to thank you not just for your commitment to public involvement, but also your desire to do it well.

Good luck.

Simon Denegri
NIHR National Director for Patients, Carers and the Public
May 2018

Acknowledgements

The Standards Partnership Development Group would like to thank everyone who has given their time and input into the development of these standards. A special thank you to all those people who have contributed to workshops and the public consultation, your input significantly shaped the final standards and influenced the process. Thank you to all those people who contributed their time, energy and valuable and supportive comments and contributions to the twitter #PPIStandards conversation.

The Public Involvement Standards Development Partnership was established in July 2016 and brings together representatives from the Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland) and the National Institute for Health and Research (England) working with an independent expert:

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National Standards for Public Involvement in Research

Introduction

‘What does good public involvement look like?’ People, teams and organisations in health research will often ask this question - of themselves as much as others. They know that high quality public involvement can make a real difference to research and to its beneficiaries. They want to evolve and improve their public involvement so it is the very best it can be.

As public involvement becomes a mainstay of UK health research, we need to support people to answer this question with greater confidence and whatever the context: whether they are a public contributor or junior researcher coming to public involvement for the very first time or an experienced Public Involvement practitioner working with their Chief Executive to guide their organisation to do even better things.

The public involvement standards produced here aim to provide people with clear, concise benchmarks for effective public involvement alongside indicators against which improvement can be monitored. They are intended to encourage approaches and behaviours which will support this: flexibility; partnership and collaboration; a learning culture; the sharing of good practice; effective communications.

The standards are the work of a Public Involvement Standards Development Partnership which brings together representatives including public contributors from the Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland) and the National Institute for Health Research (England).

Building on previous work across each of the four nations and beyond, the Partnership has involved public contributors, health professionals and researchers over the last 18 months to develop the standards. This included a highly successful consultation exercise eliciting 670 responses and discussion in many other settings. We are confident that they therefore reflect the community’s view of what matters most in public involvement in health research.

As a partnership we are committed to making these standards part of the UK’s research culture. We will be supporting and encouraging their use beginning with 10 test beds that have been selected to pilot the standards over the next 12 months. Their experience, as well as the learnings of the wider community that chooses to adopt them, will be crucial to further evolving and improving the standards so that we can integrate them into policy and practice.



Purpose of the Standards

The standards are for people and organisations that do research, support research and do public involvement to improve research. The standards could be used in different ways by different people, for example:

- **members of the public and community groups** can use the standards to assess the strengths and weaknesses of their involvement in a research project or organisation and identify how to improve that involvement
- **researchers and research organisations** can use the standards to assess their plans for public involvement and identify how to improve those plans
- **research funding agencies** can note how public involvement is being implemented in projects and organisations that they support.

They provide a framework for reflecting on and improving the purpose, quality and consistency of public involvement in research. They describe the building blocks for good public involvement and provide a baseline of expectations. This helps the public know what to expect when involved in research, and researchers know what needs to be done.

The standards are:

- a description of what good public involvement in research looks like
- designed to encourage self reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes.
- a tool to help people and organisations identify what they are doing well, and what needs improving
- intended to be used with any method or approach to public involvement in research
- adaptable to your own situation and can be used alongside other resources such as case studies, public involvement checklists, and toolkits.

The standards aren't a recommendation for any particular approach or method for public involvement in research, or about 'one way' of doing public involvement. It is possible that some organisations will achieve many of the standards and indicators, others may achieve just a few. Success is not about meeting all the standards and indicators all the time, but about improvement over time as experienced by all the people involved (public, researchers, organisations).



Definitions used in the Standards

- **Public:** In these standards we refer to the ‘public ’ throughout. When we talk about the public this also includes; patients, service users, survivors, carers and family members.
- **Public involvement in research:** Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. (NIHR INVOLVE 2017)
- **Public involvement standard:** a statement of good practice that describes one of six core elements in public involvement in research.
- **Public involvement indicator:** a statement of good practice that describes what is needed to demonstrate meeting the standard.
- **Examples:** different ways that demonstrate how you could meet the standard in different settings and contexts. These are not comprehensive and you and your organisation will be working towards, meeting or exceeding an indicator in a way that is relevant to your own setting.

Using the Standards

The Standards are intended to be used by a wide range of people and organisations doing research. They are not designed as rules, or to provide fixed ideas about public involvement in research. They aid setting realistic expectations, encourage improvement and achieve excellence in public involvement in research. Over time they can provide organisations with minimum expectations of public involvement in research.

They can be tailored to suit your situation, for example; the type of research you are doing, the amount of resource (money, people, skills) you have, and the purpose of your public involvement in research.



Standard 1: INCLUSIVE OPPORTUNITIES

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING

We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT

To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.



Standard 1: INCLUSIVE OPPORTUNITIES

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

We want research to be informed by a diversity of public experience and insight so that it leads to treatments and services which reflect our needs.

Standard 1: Indicators

1.1 We involve people affected by and interested in the research at the earliest stage

Examples of how 1.1 could be met:

- organisations encourage research teams to involve the public in the exploration of new research and/or research prioritisation processes
- research teams involve a range of public with experience of a health condition in reviewing and developing outcomes (and measurements) for clinical trials in that health condition
- an involved member of the public who has a visual impairment can expect to take part in writing research plans.

1.2 We identify and address barriers to taking up public involvement in research

Examples of how 1.2 could be met:

- organisations have an efficient payment process for out of pocket expenses and this process is reviewed regularly.
- project teams involve the public in deciding the location, timing and frequency of meetings
- involved members of the public have the option to request 'book ahead' transport so that they don't bear the cost up front.

1.3 We make information about opportunities for public involvement in research available, using different methods so that we reach relevant and interested people

Examples of how 1.3 could be met:

- an organisation has an up to date database of potential public members and communities that they can approach with opportunities for involvement
- a clinical trial team recruits young people by social media to join the research planning group
- a member of the public wants to get involved in research and is able to find and read plain language summaries of the ongoing, and planned research opportunities available.

1.4 We have fair and transparent processes for involving the public in research

Examples of how 1.4 could be met:

- organisations advertise their public involvement opportunities widely for example; website, NHS, local papers
- a research project team advertises for new people to get involved, rather than approaching the same people each time
- a member of the public expresses interest in an involvement opportunity. A short description of what they can expect is part of the information pack they receive.

1.5 We offer choice and flexibility in opportunities for public involvement in research

Examples of how 1.5 could be met:

- organisations make clearly available all the different ways that people can get involved in different types of research
- within research project teams information about everyone's different interests and aptitudes is shared and used to negotiate tasks and activity
- involved members of the public take part in regular review meetings with research partners to discuss their experiences, preferences and progress.



Standard 2: WORKING TOGETHER

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

We deliver better research when we work together on a common purpose. Different perspectives are respected and embraced through clearly defined roles and responsibilities.

Standard 2: Indicators

2.1 We jointly define and record the purpose of our public involvement activity

Examples of how 2.1 could be met:

- organisations develop and share the purpose and intended benefits of public involvement in their research
- a research team anticipates and describes what their public involvement activity will contribute to the research
- a public contributor to research is very clear what their input will achieve for the research, and that this can be adapted according to their changing needs.

2.2 We develop public involvement plans and activities together

Examples of how 2.2 could be met:

- involved public are part of the process of agreeing an organisation's research public involvement strategy
- a clinical trial team discuss with their included public the potential 'burden' of being part of the research trial, and adjust their plans as necessary
- an involved member of the public can see how and where their contribution to research plans has been incorporated.

2.3 We ensure there is shared understanding of roles, responsibilities and expectations, which may evolve over time.

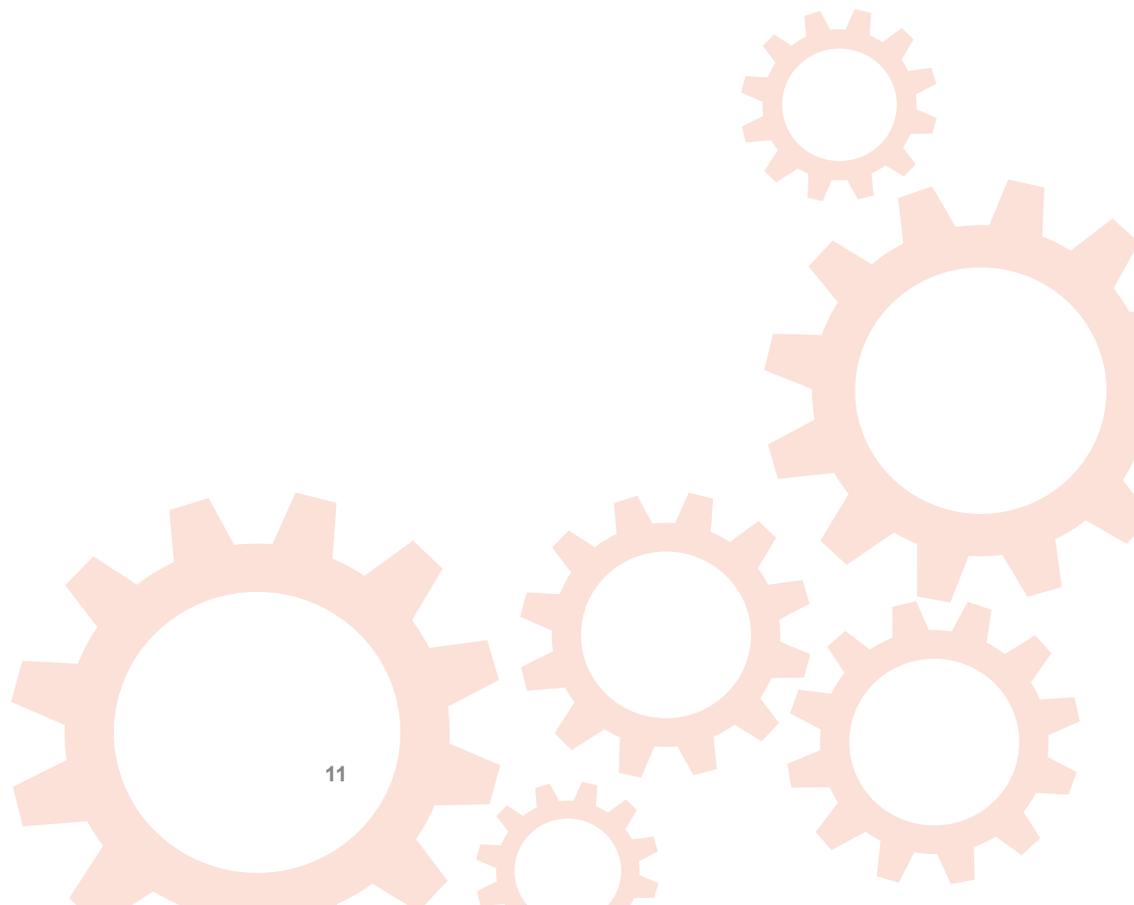
Examples of how 2.3 could be met:

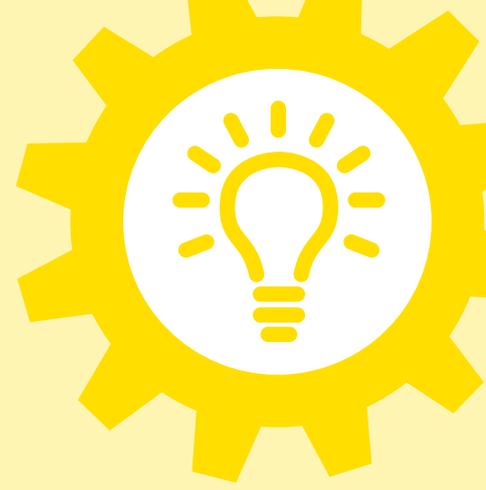
- an organisation runs an annual review with their involved public members to check on how they are finding the experience, and what can be improved
- a research team has role descriptions for everyone involved, including members of the public, that have been agreed and are reviewed
- a public member of a research team feels able to communicate how they find their role and adjust it if needed (due to health state or other reasons).

2.4 We recognise individual ideas and contributions and uphold decisions together.

Examples of how 2.4 could be met:

- organisation ensures that chairs of meetings and panels have the necessary skills (for example, active listening, encouragement to contribute) to genuinely involve public contributors in decision making
- research project Steering Group minutes describe and reflect how decisions are made for the research, and where there is contribution from the public
- public contributors give feedback on their involvement such as whether they are able to contribute their ideas, (which are actively discussed) and are involved in decision making.





Standard 3: SUPPORT & LEARNING

We offer and promote support and learning that builds confidence and skills for public involvement in research.

We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.

Standard 3: Indicators

3.1 We designate and monitor resources to ensure and support effective public involvement

Examples of how 3.1 could be met:

- an organisation requires public involvement to be part of the pre application process (for example, writing the research bid) so that public involvement budgets are costed in and reflect the reality of public involvement.
- research teams offer involved members of the public payment for work undertaken as part of the research
- public contributors are offered, and get support that is tailored to their individual needs (for example, travel, carer/child care costs, accommodation, access requirements).

3.2 We offer a range of support to address identified needs

Examples of how 3.2 could be met:

- a research organisation commits to providing access to interpreters and/or signers where needed in public involvement
- a research team recognises that an involved member of the public may need emotional support as part of being involved in research, and addresses this
- an involved member of the public who is housebound has access to video/phone conferencing hardware/software so that they can participate.

3.3 We have a clearly identified point of contact for information and support

Examples of how 3.3 could be met:

- a research organisation has a public involvement section or page on its website with contact details for a named public involvement lead.
- a research team has a named public involvement person and contact details (telephone and email) that are easy to find and accessible
- an involved member of the public can leave a message with the research organisation and will get a response within an agreed timeframe.

3.4 We develop, deliver and monitor learning opportunities in partnership, for all involved in research

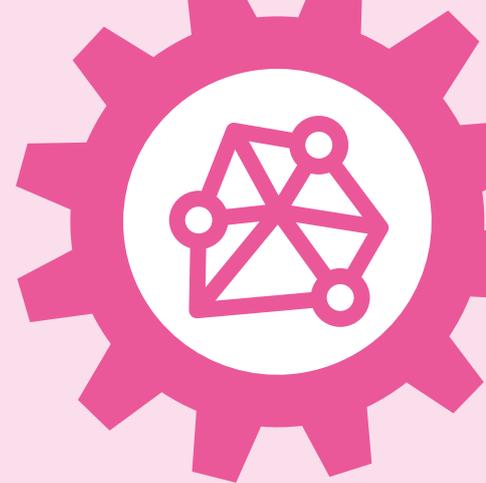
Examples of how 3.4 could be met:

- a research organisation compiles a record of, or annual learning report that describes the public involvement learning activity and uptake
- the team develops an induction programme or process to introduce public members to the study, and discuss support needs and training
- public contributors are partners in designing and delivering public involvement support and learning activities.

3.5 We actively learn from others, we build on what we have learned and share our learning

Examples of how 3.5 could be met:

- a research organisation supports a shared learning group for all of its research project teams, so that learning is shared and built upon
- a research project team reviews its progress regularly, including how it is doing in involving the public in research
- public involvement knowledge and skills developed over time by public contributors forms part of the induction of new public contributors – for example learning and support workshops
- involved members of the public are involved in any review of public involvement and research.



Standard 4: COMMUNICATIONS

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Plain language helps develop shared understanding in research. Free flow of information and adapting communication for particular needs helps keep the focus of involvement on improving research and outcomes.

Standard 4: Indicators

4.1 We develop and deliver a communications plan for our involvement activities

Examples of how 4.1 could be met:

- a research organisation develops and delivers a local communications plan to support a national campaign for example 'I Am Research'
- a research team includes a summary of its communication plan (target population and research beneficiaries) in its funding application
- public contributors are kept well informed by ensuring key messages are written in plain language, use methods and routes that will reach them, and sent in good time.

4.2 We are inclusive and flexible in our communication methods to meet the needs of different people

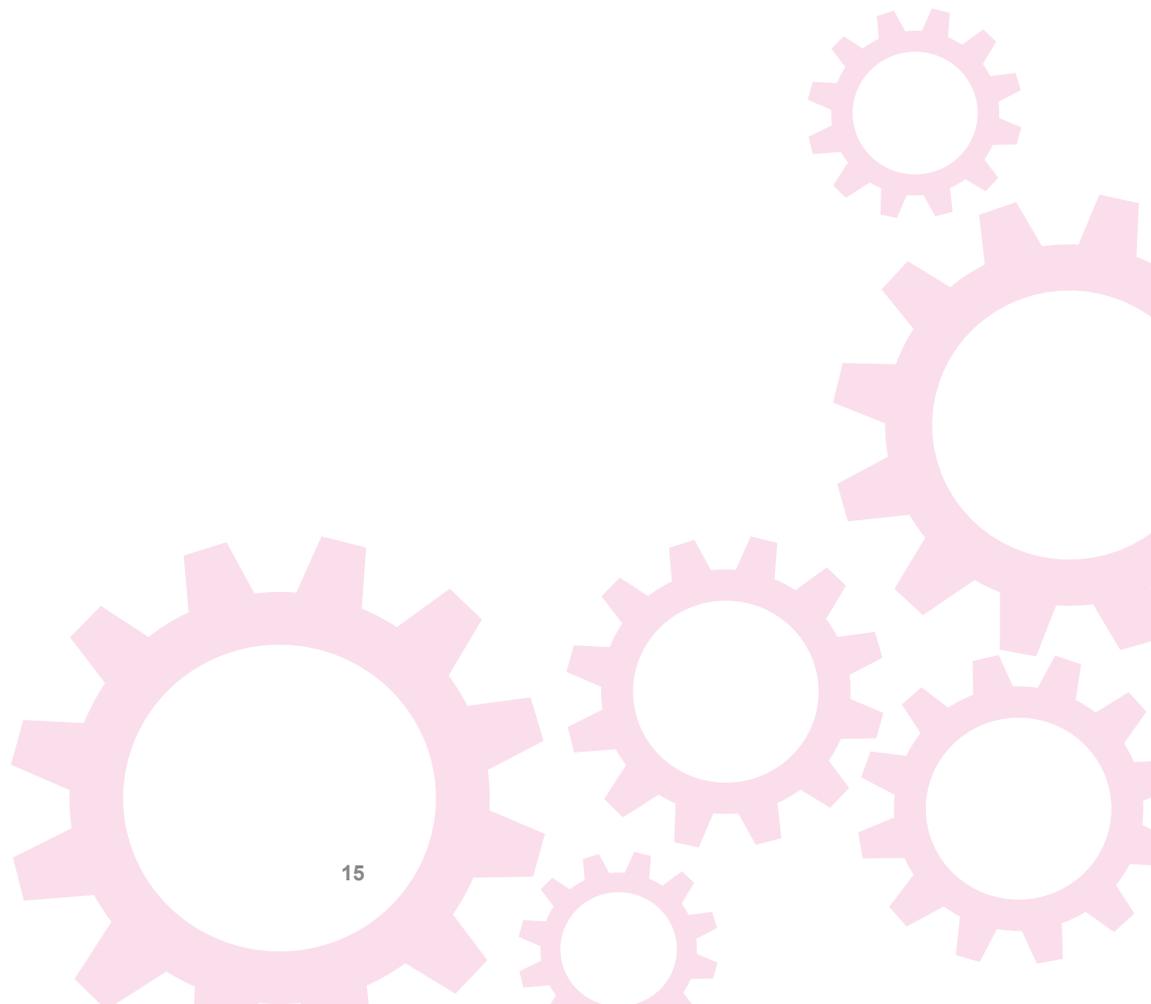
Examples of how 4.2 could be met:

- an organisation will make information available in different formats, such as easy read or large print, upon request.
- project teams identify where there is a need to provide public involvement information in different languages or through different methods (for example, email, phone call, social media, postal, face to face)
- an involved member of the public can ask for, and easily access information in different formats for example for visual impairment.

4.3 We gather, offer and act on feedback, which we then share.

Examples of how 4.3 could be met:

- the organisation asks involved members of the public about their experiences of working with the organisation and as a result changes its practice.
- research project team adopts a 'You said - we did' model of communicating
- public contributors routinely hear from and about the research project or organisation that they are involved in, and how their contribution is making a difference.





Standard 5: IMPACT

To drive improvement, we capture and share the difference that public involvement makes to research.

We can learn from both positive and negative impacts of public involvement in research. By sharing this learning we can improve what we do.

Standard 5: Indicators

5.1 We involve the public in the assessment of public involvement in research

Examples of how 5.1 could be met:

- a research organisation sets up a group of public advisors to work with them to assess whether intended outcomes and impact of public involvement have been achieved
- the team works with public members to develop the evaluation process for public involvement for example a workshop to reflect on the impact of public involvement in the project both on the research and the people involved
- public contributors are part of the team that writes an annual progress report on the delivery of public involvement plans.

5.2 We record our agreed purpose for public involvement and its intended outcomes

Examples of how 5.2 could be met:

- a research organisation clearly states in their plans what they want to achieve as a result of public involvement in their activities
- a research team discusses and records expectations of outcomes of involvement before the research starts
- public contributors are involved in agreeing the intended outcomes of public involvement in research.

5.3 We collect information that will help us assess the impact of public involvement in research.

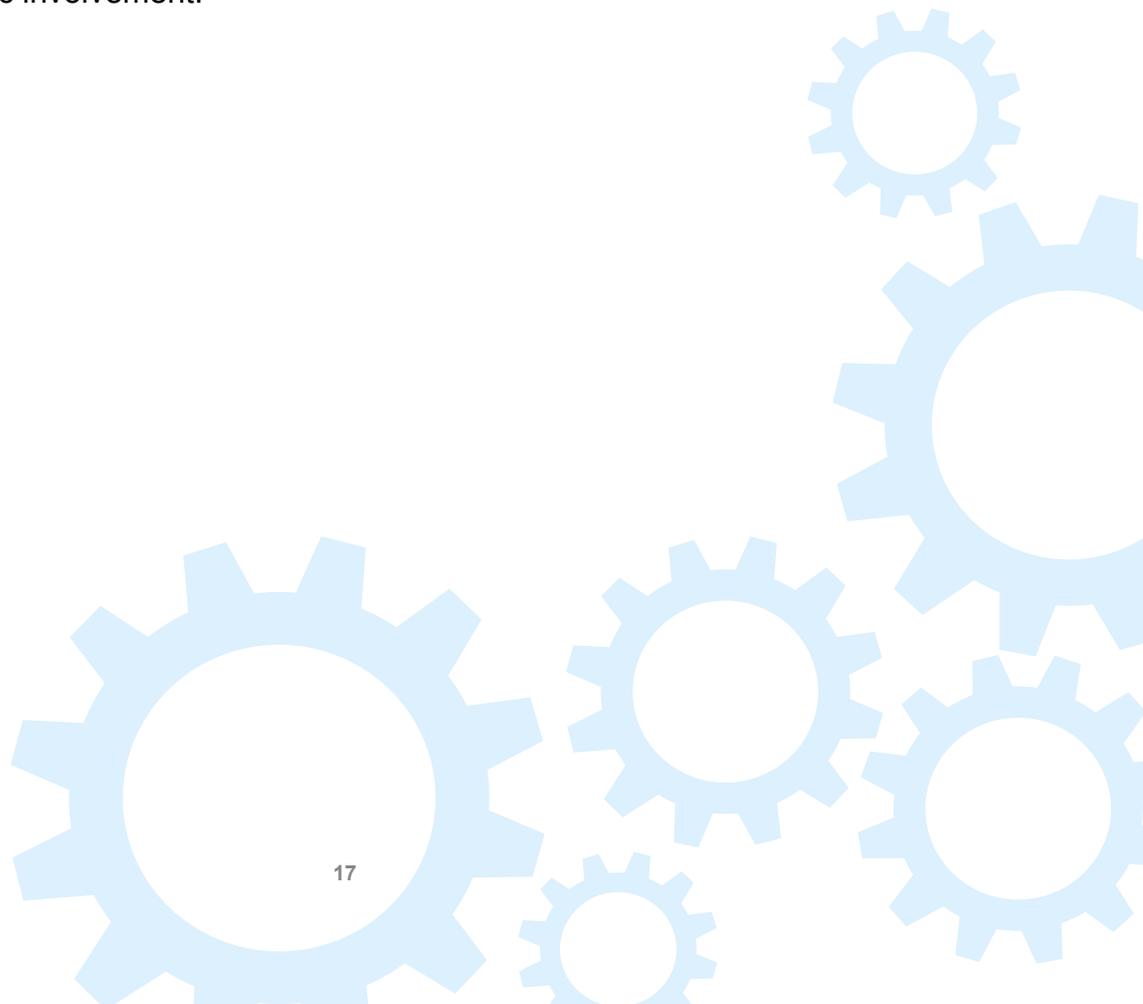
Examples of how 5.3 could be met:

- a research organisation collects information about public involvement in both successful and unsuccessful funding applications, and reviews this information
- a project team collects information over time to help demonstrate whether or not the intended outcomes of public involvement have been achieved
- feedback from public contributor on their experience of public involvement in a research project or organisation is routinely recorded, monitored, reported and acted on.

5.4 We reflect, learn and report the extent to which we have met our intended purpose and predicted outcomes.

Examples of how 5.4 could be met:

- an organisation publishes an annual report on the delivery of its public involvement plan including an assessment of impact and its future plans
- in publications, a research team writes about its public involvement activities and any impacts of public involvement and publishes this as well as using the learning from the project to inform future projects
- a public contributor can access case studies and reports that demonstrate the impact of public involvement.





Standard 6: GOVERNANCE

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

Public involvement in research needs visible leadership and clear lines of responsibility so that it is transparent and gains public trust.

Standard 6: Indicators

6.1 Public voices are heard, valued and included in decision making

Examples of how 6.1 could be met:

- public contributors participate in senior level decision making groups
- public contributors are part of decision making from the outset of projects
- involved public contribute to the conversation, are listened to, and their appropriate views are reflected in the final decisions made.

6.2 We have public involvement strategies and/or plans in place that we regularly monitor, review and report on

Examples of how 6.2 could be met:

- a research organisation monitors and reports on its public involvement strategy, for example the objectives of public involvement in research and intended outcomes
- public involvement is a standing agenda item at senior management meetings
- a research team plans the public involvement in their project and then monitors and reviews what they do to learn and improve
- public contributors are decision makers in developing, delivering, monitoring, reviewing and reporting plans for public involvement in research.

6.3 Responsibility for public involvement is visible and accountable throughout our management structure

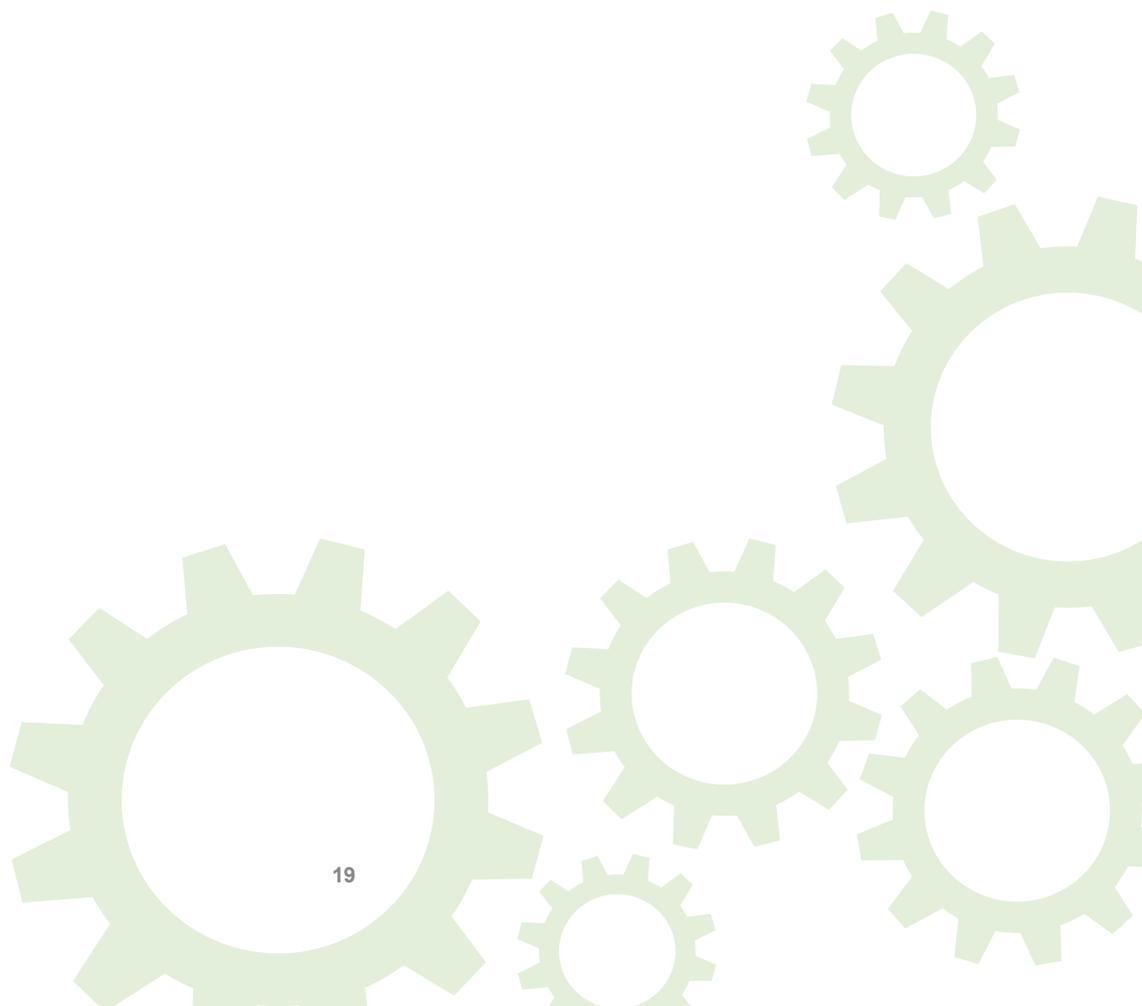
Examples of how 6.3 could be met:

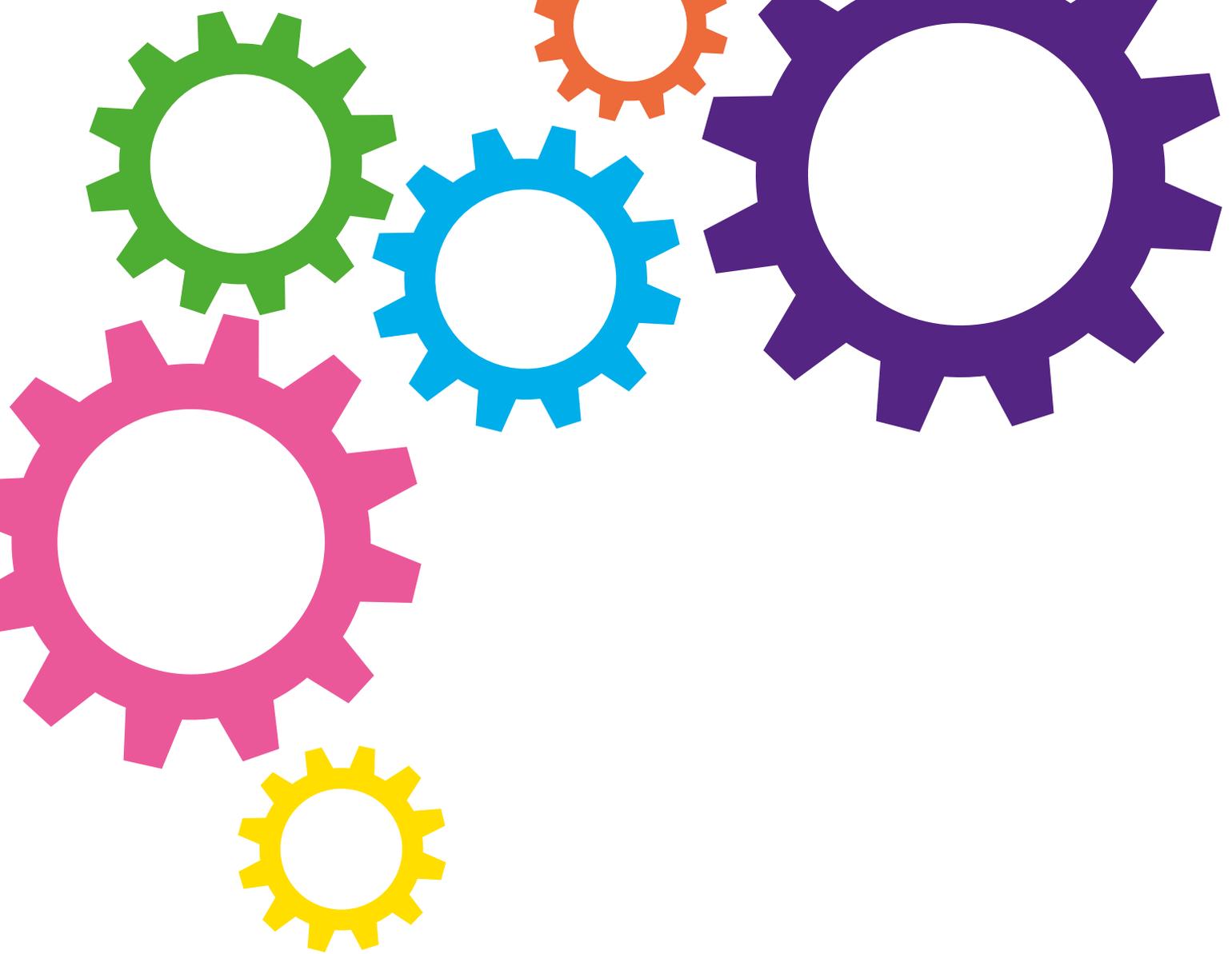
- an organisation has a publicly accessible plan for public involvement in research plan which sets out requirements for public involvement in individual studies and names a member of the senior management team responsible
- public contributors can identify who they should approach in a research team or organisation whether they want to raise a practical query or make a complaint
- public members are consulted about what resources might be needed to undertake public involvement effectively.

6.4 We allocate money and other resources for public involvement.

Examples of how 6.4 could be met:

- a research organisation has a designated public involvement budget that supports their public involvement plan, this is reviewed regularly
- a research team keeps records of resources so that this information can be used for project review, and design and proposals of future research and public involvement
- public contributors are involved in decision making about the allocation of resources for public involvement.





For more information about the Standards for Public Involvement, please visit:
<https://sites.google.com/nih.ac.uk/pi-standards/home>

If you would like an Easy Read booklet about the standards, please contact us:

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