How to Co-Design digital inclusion in Health

A pathfinder model

July 2019

Good Things
Foundation

Contents

Introduction

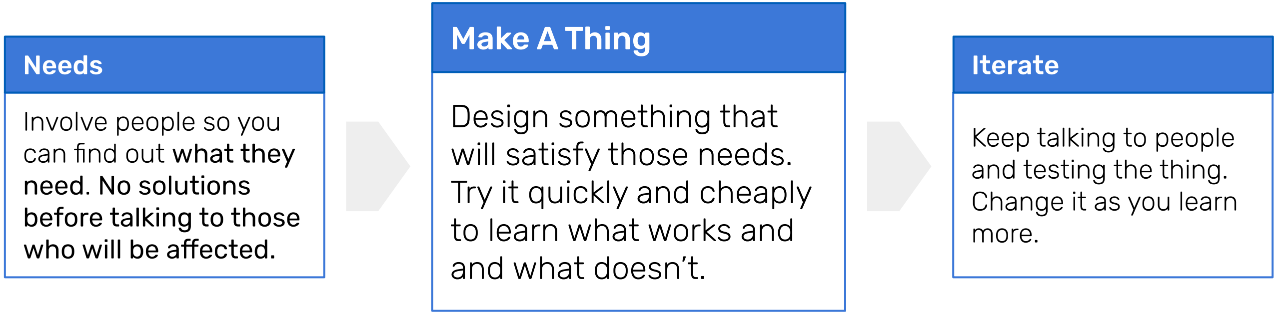
Co-design is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of design. Whether you are designing digital products, patient pathways or both it is important that everyone affected has the opportunity to input into the process.

“Nothing about us without us” has been a mantra used by a host of excluded groups over the past 20 years and it has never been more important than in a digital age where poor design can increase health inequalities by further exclusion.

Good Things Foundation have adopted a co-design approach to the NHS Widening Digital Participation programme. This approach has allowed us to:

1. Have as much impact as possible in a short space of time
2. Leave a lasting legacy for those areas involved, with people’s voices being heard and services being continually improved.

This guide shows how you can introduce co-design into your work with useful tips to get started.



Needs

Involve people so you can find out what they need. No solutions before talking to those who will be affected.

Make A Thing

Design something that will satisfy those needs. Try it quickly and cheaply to learn what works and and what doesn’t.

Iterate

Keep talking to people and testing the thing. Change it as you learn more.

Co-design model

STAGE 1:
UNDERSTAND and
DEFINE

User needs

User needs not wants. Spend time with people to understand their needs.

Stakeholder needs

Understand their pressures, expertise, view of current system and how things can improve

STAGE 2: IDEAS and
PROTOTYPE

The thing

Create a set of recommendations to try out. Using things that already exist to prove concept

STAGE 3:
TEST

Iterate

Try it for a while. Take stock. Find out what is working and what isn’t then iterate

Deliver

Deliver and evaluate

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STAGE 1: Understand and Define - User Needs

The first thing we want to do is to understand the lives and circumstances of the people your project will affect - as much as possible (often called user research or user insights).

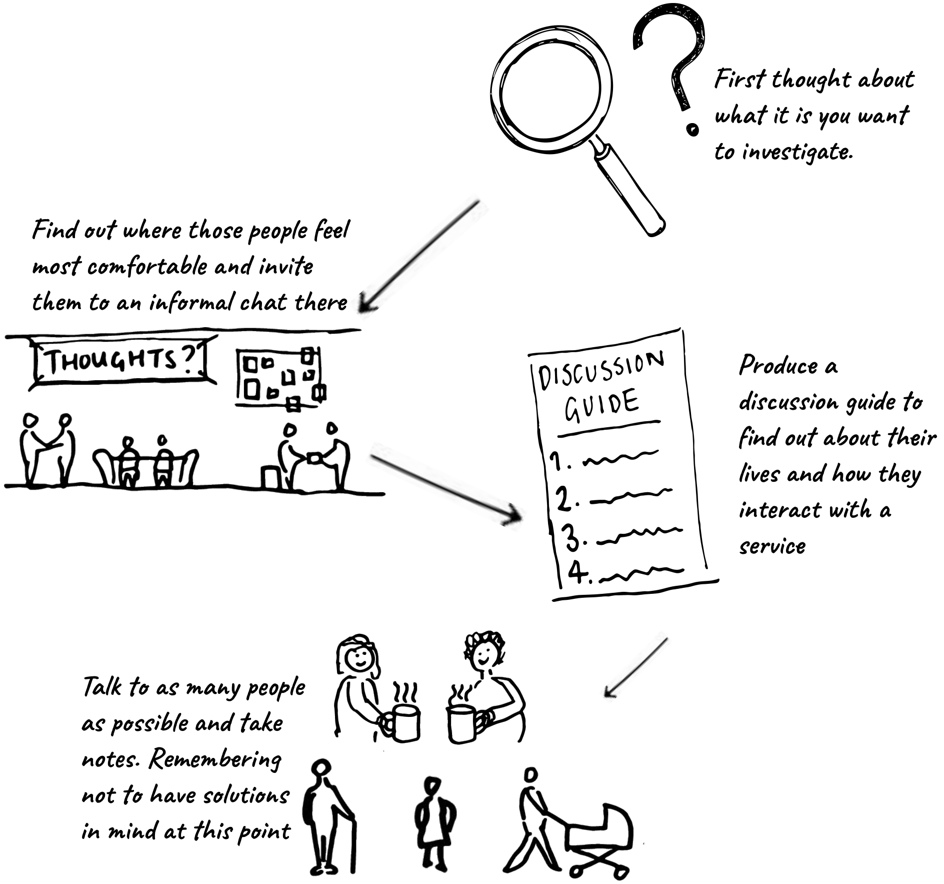
In order to get the best out of these conversations is it important to consider the following

Go where the people are - conversations are more open and honest when people feel comfortable and safe. Spend time where they spend time. Don’t ask them to come to a formal building as it shifts the power dynamic. Consider your local community spaces e.g. any of the community centres in the Online Centre Network

What’s important to them - you will be discussing sensitive topics. It is important to capture people’s views (even if you don’t think it is linked to your project specifically.) It all adds to the context in which you are working

Understand needs not wants - keep asking *why.* This allows you to understand the underlying reasons for the solutions that people might propose

No solutions - if you approach these sessions with a predetermined solution you will accidently lead your findings that way.



First thought about what it is you want to investigate.

Find out where those people feel most comfortable and invite them to an informal chat there

Produce a discussion guide to find out about their lives and how they interact with a service

Talk to as many people as possible and take notes. Remembering not to have solutions in mind at this point

STAGE 1: Understand and define - User Needs

Don't:

- Ask people to go to somewhere new. You have to go to them
- Question wrong information. This is about understanding things from that person's perspective

Do:

- Go where the people are
- Make notes on post-its (they are easier to sort into themes back at the office)
- Have a discussion guide to help you (but make conversations natural. Allow it to flow where the person takes it)

Don't:

- Assume a solution beforehand and try and ask if this would work
- Worry that you will get conflicting statements from people. This is part of the challenge in design

Do:

- Bring all your notes back to the office and try and sort statements into themes and needs (we would call this affinity sorting)
- Get colleagues to help you so you can talk things through with them
- Offer vouchers for participation in a discussion. This is their time and you are getting valuable insights from them

STAGE 1: Understand and Define - Stakeholder Needs

We run design workshops for between 20-30 stakeholders (including front line staff, budget holders, patient advocacy groups and 3rd sector orgs) to begin to understand their needs, processes, frustrations and ideas.

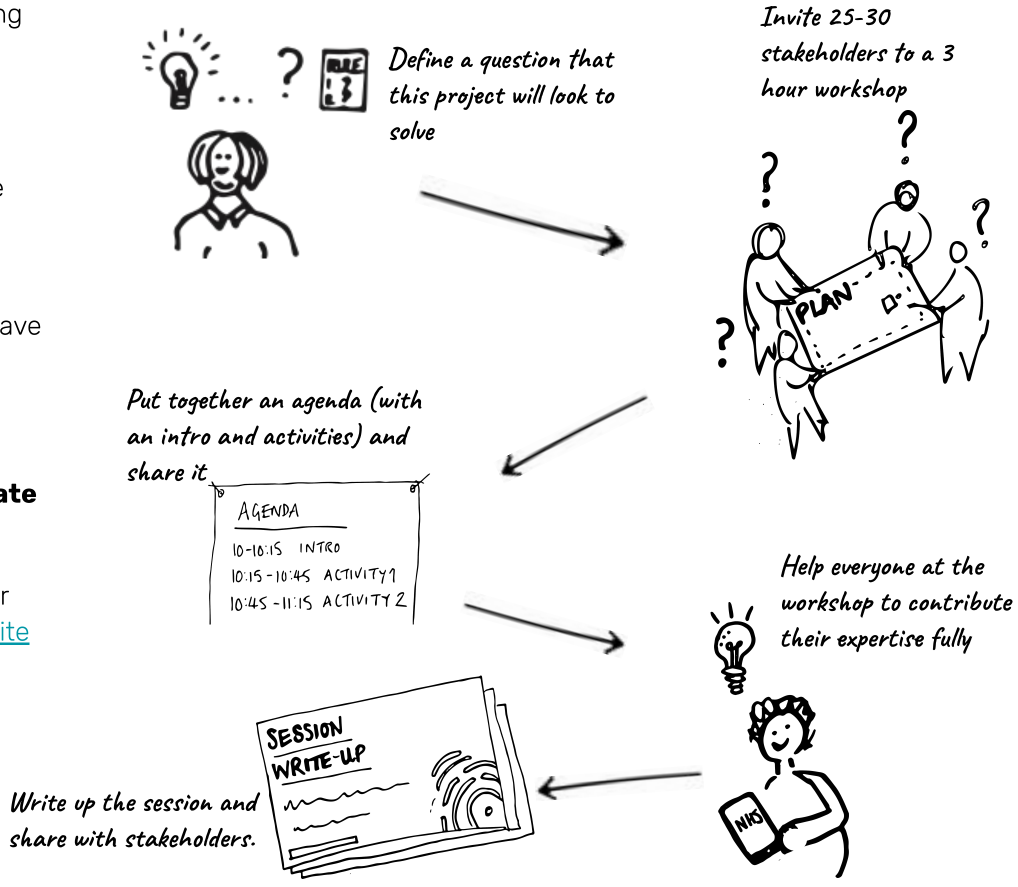
For the Stakeholder Needs session we start with a question that we want the workshop (and project) to try and answer.

We then work through a series of exercises to understand what is happening now, what is good/bad about it and what areas do we have scope to change.

The important principle of this workshop is

Everyone in the room is an expert in their field, you must create space for everyone to contribute fully.

Note: These workshops are all different and designed specifically for each problem we are looking to solve but here is a template and write up from our Cancer pathfinder.



Define a question that this project will look to solve

Invite 25-30 stakeholders to a 3 hour workshop

Put together an agenda (with an intro and activities) and share it

Help everyone at the workshop to contribute their expertise fully

Write up the session and share with stakeholders.

STAGE 1: Understand and define - Stakeholder Needs

Don't:

- Underestimate the power of giving people permission to express their frustrations in a safe space
- Be afraid to have a 'parked' issues log. So people can be heard, even if it isn't relevant for that day

Do:

- Know that your role in this workshop is to facilitate conversations not suggest ideas. They are the experts
- Bring colleagues with you to take notes (because some things may just be said and not written down)

Don't:

- Think that you will get 'the answer' in this session. Stakeholders will have ideas and they will be useful. However, it's important to take all of the information back to the office and see what has emerged

Do:

- Be flexible with the workshop. This is difficult, but if the exercises aren't working you need to be able to change things
- Get people moving around the room and change their groups. It exposes people to other perspectives and keeps energy in the room

STAGE 2: Ideas and Prototype

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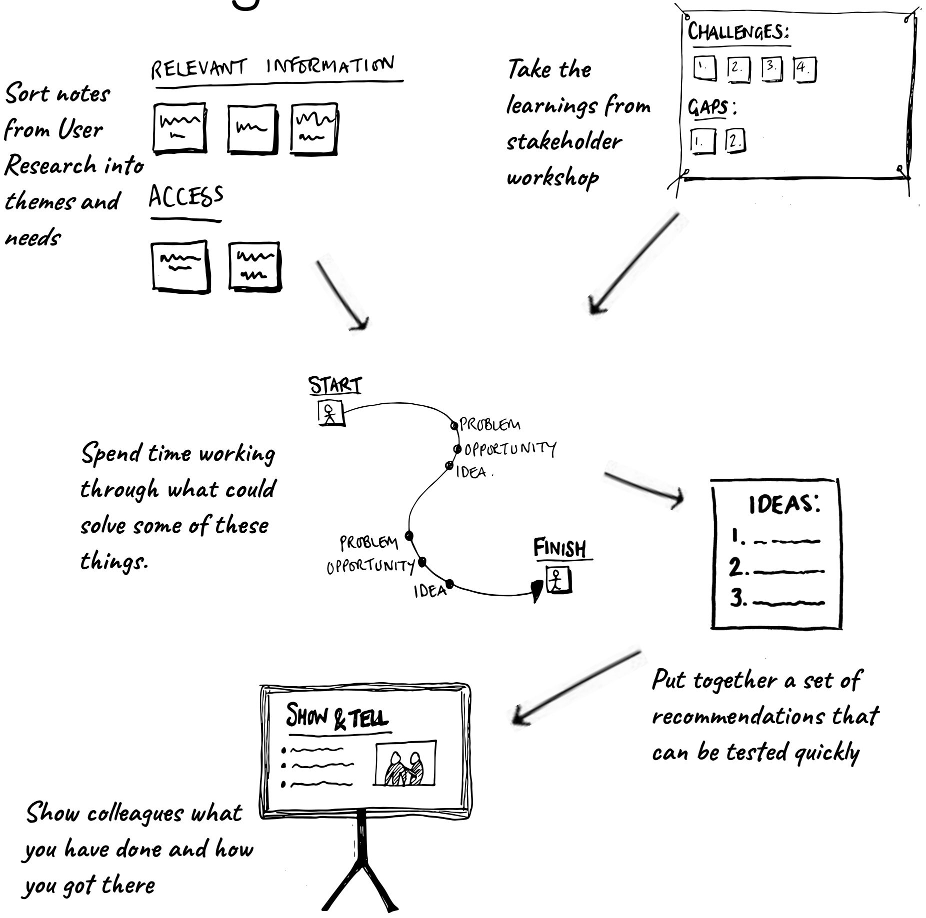
STAGE 2: Ideas and Prototype - the thing

This stage focuses on what *the thing* is that you can try. This could be a product, service, new model of care or even a tweak to an existing thing; based on all of the insights that you have found out during the previous stage.

1. Take all of your **user needs** work and sort into themes (affinity sorting). Write these themes up along with context.
E.g. '<u>Relevant information</u>: people need to know specific things about information at a time that suits them. Stacks of leaflets do not satisfy this as people lose them or don't know where to start'

2. Take all of your stakeholder workshop work and show where there are areas for improvement/re-design in processes that already exist
E.g. '<u>Lack of time for professionals</u>: Health professionals are under extreme time pressures and therefore a project can't add more burden. It must be something simple that yields results'

Provide a set of recommendations that are quick and easy to try and test. See an example from our [Dementia pathfinder]



Sort notes from User Research into themes and needs

Take the learnings from stakeholder workshop

Spend time working through what could solve some of these things.

Put together a set of recommendations that can be tested quickly

Show colleagues what you have done and how you got there

STAGE 2: Ideas and Prototype - The Thing

Don't:

- Think that this will be easy. It takes time and effort to understand all of the insights you have gathered. The more you talk about it the clearer it will become
- Think that this is finished. Affinity sorting can go through several rounds before you feel that it articulates the needs of the people you spoke to

Do:

- Use things that are readily available as this is about testing concepts at this stage. We have used facebook, PDF's and physical places that already exist to test things
- Talk things through with colleagues. They will notice things that you haven't (because you will be so close to it it's easy to lose perspective)

Don't:

- Assume this will be the perfect thing that you design. It will be a good starting point - nothing more
- Keep things to yourself. More perspectives improve things. Invite people (users, managers etc) to see what you have found out and bring them on that journey with you

Do:

- Feel that you are an advocate for those people. Think **"would this work for XXXXXXXX"** who you spoke to
- Set challenging time scales. You will learn so much from just getting *the thing* out there with a few people

STAGE 3: Test

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STAGE 3: Test - Iterate

Your recommendations from Stage 2 will hopefully be easy to test.

This stage is about getting *the thing* out there with a small number of people so you can see how it works - in a live situation.

Have one or two professionals test the new *thing* (model/product/journey) with twenty to thirty people (patients, users) to see how it works.

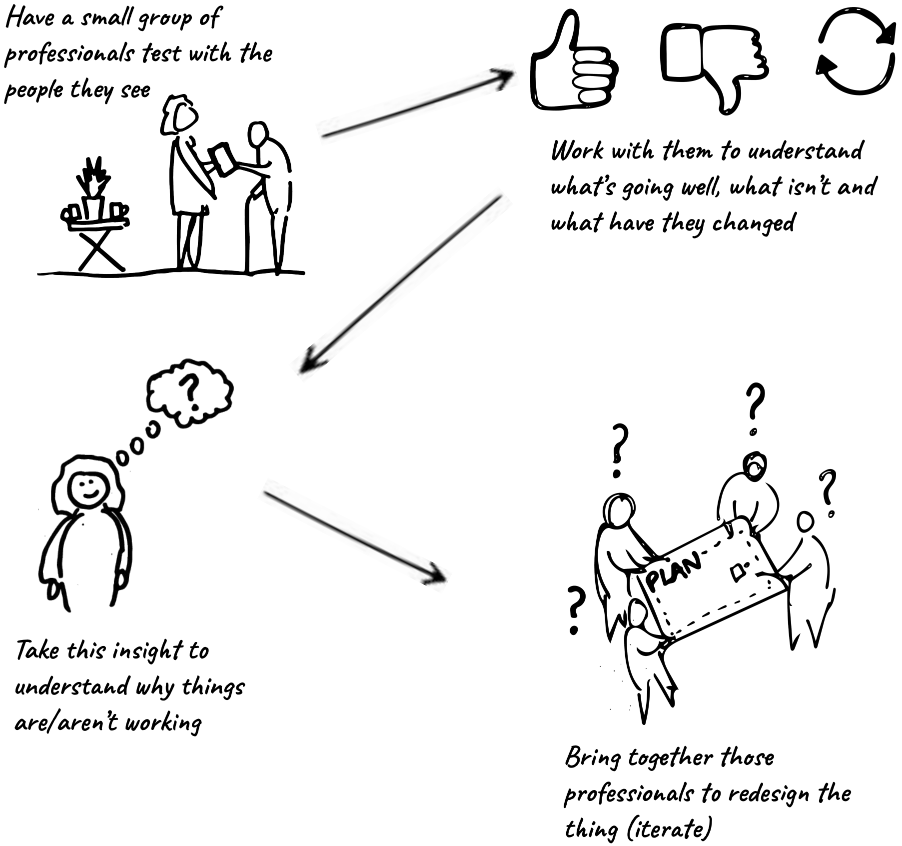
Gather information on what works, what doesn't work and what are they doing differently to the original recommendations.

Your main objective is to find out

1. Is this a viable thing to take forward (with some changes)
2. Why it is working / not working in certain parts

Then, once you have gathered enough insights, you can make changes (iterate) and get it back out there to more people.

The iterated thing should then run for 6 months. Work with an evaluator at this stage to find out what evidence you need to collect to prove outcomes and impact



Have a small group of professionals test with the people they see

Work with them to understand what's going well, what isn't and what have they changed

Take this insight to understand why things are/aren't working

Bring together those professionals to redesign the thing (iterate)

STAGE 3: Test - Iterate

Don’t:

- Be afraid if it doesn’t work. This process is designed to limit investment in *good* ideas that **don’t work** in practice (failing fast)
- Think you need to ‘get the thing right first time’. At this stage we want the quickest thing that does the job (minimal viable product) so we can test that people use it/interact with it

Do:

- Remember this is about proving the concept for wider implementation
- Be completely open with findings. Being open makes things better

Don’t:

- Be wed to the idea. Part of the value of co-design is that it isn’t your idea. This means that you can make objective decisions about it moving forward
- Just use the same people for testing that you used in the initial user research. Widen the testing pool if you can

Do:

- Document the changes and the reasons for it. It will help colleagues learn about what doesn’t work in practice
- Remember that things aren’t done in isolation. Everything that you are asking health professionals to implement is part of a matrix of things they are already doing

STAGE 3: Test - Deliver

By now *the thing* will be in good shape to roll out further. Remember that services are never ‘finished’ and they should continually evolve.

You have proven the concept and changed the bits that don’t work.

The project now needs some time to be consistently embedded and measured.

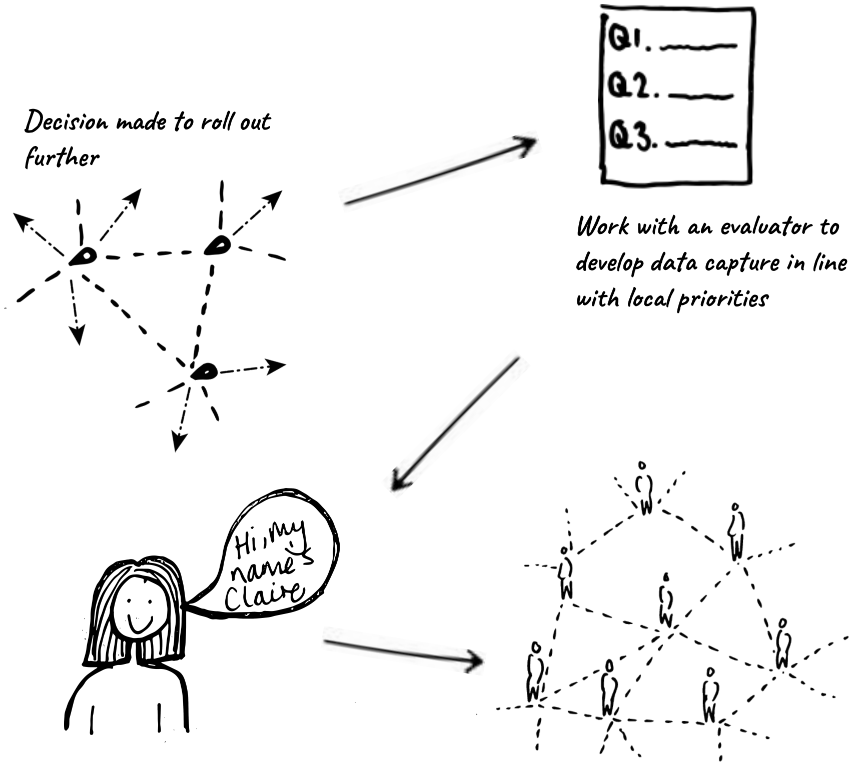
Is *the thing* about an improvement to an existing service or proving something new is needed (and therefore extra money will be needed)?

Considerations for measurement

1. What is most important to your local goals / vision (if this is return on investment or health improvements etc etc)
2. Use recognised tools for measuring improvements e.g. WEMWBS
3. Using reduction in GP appointments or other such indicators for return on investment

Collect this data over the next 6 months along with monthly update calls/ visits so you can capture other insights along the way.

4. Case studies are powerful. Collect user (people, patient) and health professional case studies to back up the statistical evidence



Decision made to roll out further

Work with an evaluator to develop data capture in line with local priorities

Begin to capture case studies so you can keep stakeholders up to date with progress

Be proactive in sharing what you are doing and invite other orgs/ teams to get involved

STAGE 3: Test - Deliver

Don’t:

- Think that life changing health outcomes happen over night for people who are excluded.
- Forget to keep pushing to test this with more and more excluded individuals

Do:

- Make data collection as easy as possible. Projects can be ruined when data collection is such as administrative burden it gets in the way of doing the thing
- Provide consistent data collection mechanisms for everyone involved

Don’t:

- Assume one size fits all
- Think that a service is ‘finished’ after 12 months of a pathfinder

Do:

- Make things as simple as possible
- Involve professional evaluators to help with your outcomes work

In your area

This is how we have done co-design through the NHS Widening Digital Participation Programme.

It will never be a smooth process as people's lives are complex and varied.

Hopefully, this guide gives you some information on how to get started in your area.The stages are there for reference and for you to adapt to your own locality.

If you would like to learn more about co-design in health please don't hesitate to contact pete@goodthingsfoundation,org

Assets

Stakeholder workshop template and write up
Recommendations from Dementia pathfinder
Warwick Edinburgh Wellbeing Scale WEMWBS
Costs for reduction in GP appointments
Online Centre Network

NHS Widening Digital Participation

Further Reading

Experience based Co-design toolkit - The Point of Care Foundation
Patients and staff as Co-designers in Healthcare - British Medical Journal (BMJ)
Experience based co-design in acute healthcare services - JBI database of systematic reviews and implementation reports
NHS Service Design Principles - NHS Digital

Glossary

Here we put our definitions to some of the terms that have been mentioned within this guide. Although we have tried to take out as much jargon as possible (or explain and jargon within the text) it is not always possible.

Co-design – is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of design.

Users – the people who will be affected by the thing. Often this is a patient but can also be a carer, health professional, manager – depending on what the thing is

Pathfinder – is the term we use for a 12 month project that is using co-design to improve services, products or patient journeys

Iterate – is to change something based on finding out why is isn’t working

Stakeholders – are people who are invested in the process or project. This could be commissioners, people delivering the service or senior managers, budget holders and/or 3rd party deliverers

Affinity Sort – the process of taking all the comments made by users and grouping them together to create themes

User Needs – the thing that a user needs in order to do something. This takes into account the context in which they are trying to do something and barriers that stop them

The Thing – references whatever change you are trying to make through your co-design. It could be a new product, a new service, something newly commissioned or a tweak to things that already exist