

Supporting people with cancer

A How To Guide for
digital inclusion in health

March 2020



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Introduction

“cancer can turn your world upside down. But you are still you: mums, dads, friends, lovers, work mates and more.” ([Macmillan website](#) 2020)

We know that there are medical, emotional and practical things to consider when someone has been diagnosed with cancer. This Pathfinder set out to investigate how digital might be able to help support in those areas, in a manner and time that is suitable for the person.

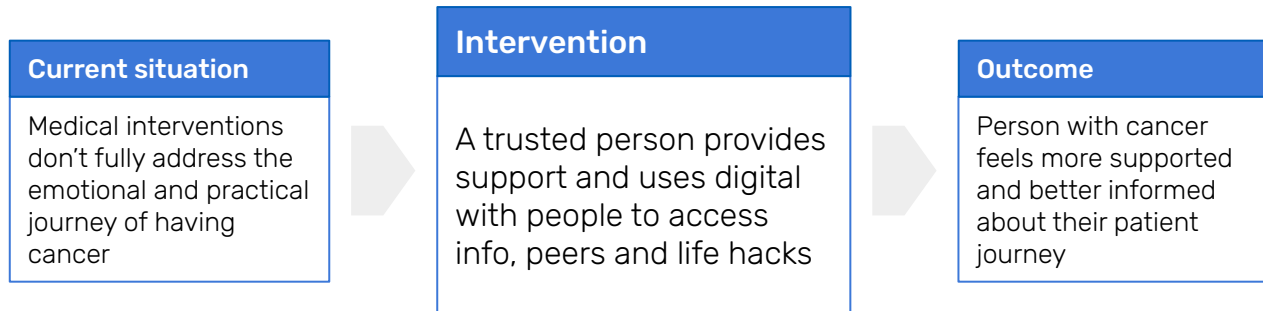
We found out some of the things that people living with cancer need

- Information about their diagnosis at their fingertips, when they need it
- Reassurance - that things are ok

- To be able to tell a health professional how they are feeling after treatment (and not just immediately after), and to be offered or signposted to a range of relevant holistic support
- To believe they are entitled to support
- To realise they're not on their own (“It’s not just me”)
- To get used to a “new normal” after a diagnosis
- To see professionals they know like nurses, support workers, and surgeons

Digital can be part of the ways that people continue to live the most fulfilling life they can. It is not the whole solution!

This guide shows what we did and what we learned so other areas can try something similar.



Intervention model

STAGE 1: Making connections

1

Spend time with pre established cancer support services

1a

Focus groups to determine barriers and ideal outcomes (Co-Design)

STAGE 2: Training

2

Training staff, volunteers and carers as Digital Champions

STAGE 3 Support

3

Meet people where they feel most comfortable

3a

Set up a closed Facebook Group

4

Meet people where they feel most comfortable and introduce digital tools that might help

4a

Encourage peer to peer support within the group

STAGE 4: Try This

5

Provide initial list of things to try and be built on locally

Stage 1: Making Connections

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Stage 1: Making Connections

Understanding local cancer Support

It's important to spend time understanding what is already going on in the local area. This could be NHS funded services, 3rd Sector Organisations' support groups and a raft of things in between. You may not find everything at once, but building relationships in the first instance is vital to gain buy in. **NOTE:** it is the people in these roles that are trusted by people living with cancer and will therefore be best placed to introduce the benefits of digital.

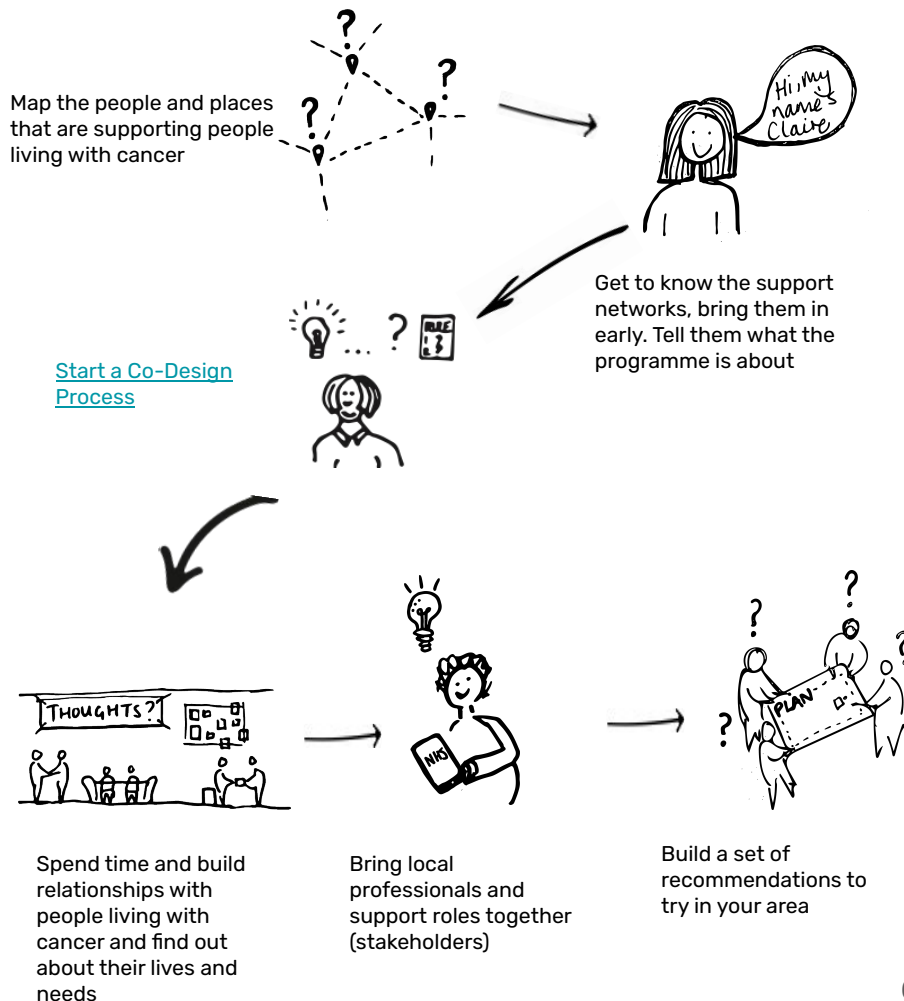
Co-Design -with, not for

New programmes need to be relevant to local areas. This guide can be a start but it won't (and can't) have all the answers for every local area. Begin the co-design process by spending time with the people who are living with cancer. Go to where they go and discuss their lives and their priorities with them.

Then gather your stakeholders: cancer specialists, front line colleagues, 3rd sector orgs and commissioners to discuss your findings and come up with somethings to try (which may or may not be in this guide)

Here's what we did in Nottingham:

[User Research Stakeholder](#) - and design session [slides](#)



Stage 1: Making Connections

People who are needed (not exhaustive)

Senior Stakeholder from local NHS trust or CCG

Senior Clinician who who can sponsor the programme

Staff and Volunteers who spend time supporting people with cancer in the places that are best for the person

Organisations who work with people with cancer (whether through their mission or CSR programmes)

Digital Project Manager/Digital Champion Trainer to run the project, map the provision in the area, make contact and start co-design sessions

Resources that are needed

List of the provision and/or people whom you will be contacting

Facilities to conduct co-design session

[Slide](#) **Template** for running the stakeholder session

Examples of good practice in other parts of the country. E.g other pathfinders found in Good Things Foundation [Digital Health Lab](#)

Stage 1: Making Connections

Don't:

- Assume that all organisations will immediately be on board. - go where the energy is

Do:

- Remember these things take time. There are lots of strands to cancer journeys and getting everyone on board will take time
- Remember that taking time to set things up will inevitably mean that iterating will be difficult - make sure you give staff/volunteers freedom to try things

Don't:

- Just send in a "Digital Champion". This didn't work for us. People need trusted, familiar faces who offer the right thing at the right time to be their digital champions.
- Treat 'digital' as something separate. All we are doing is increasing the toolkit of people who support those with cancer every day

Do:

- Think carefully about where is the best place and time to deliver this. It's where/when people feel most comfortable
- Remember the best people to deliver this are those who know something personal about the person with cancer. E.g. Their partner's name, if they have a pet, what football team they support. It's that level of familiarity that builds trust

STAGE 2: Training

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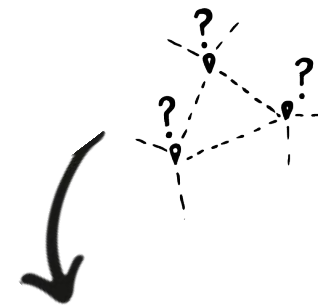
STAGE 2: Training

Through the Co-Design process you will have developed a list of people who support those with cancer and are willing to be involved in the project.

The next step is to train those people as “Digital Champions” - it works better when trusted individuals become digital champions instead of parachuting strange people into sessions as “Digital Champions” i.e. try and make ‘digital champions’ from the places where people go and with whom they spend their time.

[Here](#), you can find the training materials used in Nottingham

Be aware that everyone is busy and you will be asking for people’s time to come and be trained. Certificates can help, as it can be used as evidence of CPD (Continued Professional Development) and also brings people together as part of a movement.



Use your list of local provision to identify early adopters



Book training in with them (at their place of work). You go to them.

Give training ([example here](#)). Allow them to explore the devices. Establish that they don't have to have all the answers to be Digital Champions



Provide a [certificate](#) as a “Digital Champion”.



STAGE 2: Training

People who are needed (not exhaustive)

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Senior Clinician who who can sponsor the programme

Staff and Volunteers who spend time supporting people with cancer in the places that are best for the person

Organisations who work with people with cancer (whether through their mission or CSR programmes)

Digital Project Manager/Digital Champion Trainer to run the project, map the provision in the area, make contact and start co-design sessions

Resources that are needed

[Training Slides](#) for things to cover with trainees

A room to deliver training in

Certificates to help with confidence and create your own 'digital champion' movement

Tablets to use during the sessions

Handouts to support with using the equipment and suggested resources.

STAGE 2: Training

Don't:

- Think everyone is going to be comfortable being labelled a "Digital Champion". Use whatever term is appropriate
- Try and make digital the solution to all problems. This is about helping people get information that they need and adjust to a new life

Do:

- Make sure everyone is aware that they don't have to have all of the answers when talking to people. This is about exploring together
- Try and get groups together to train up at once. They will be able to share ideas both now and in the future
- Identify people's digital skills and confidence levels

Don't:

- Be afraid of offering to go to some one-on-one sessions with your new digital champions to support them in the first instance
- Use Jargon

Do:

- Offer examples of how it has worked in other places, but allow for the new digital champions to explore things for themselves
- Understand not everyone may be enthusiastic and positive, but having some positive people driving the work can make a massive difference and impact on others.

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STAGE 3: Support

Tablets and Wifi

Some infrastructure needs to be in place i.e. tablets and WiFi (dongles)

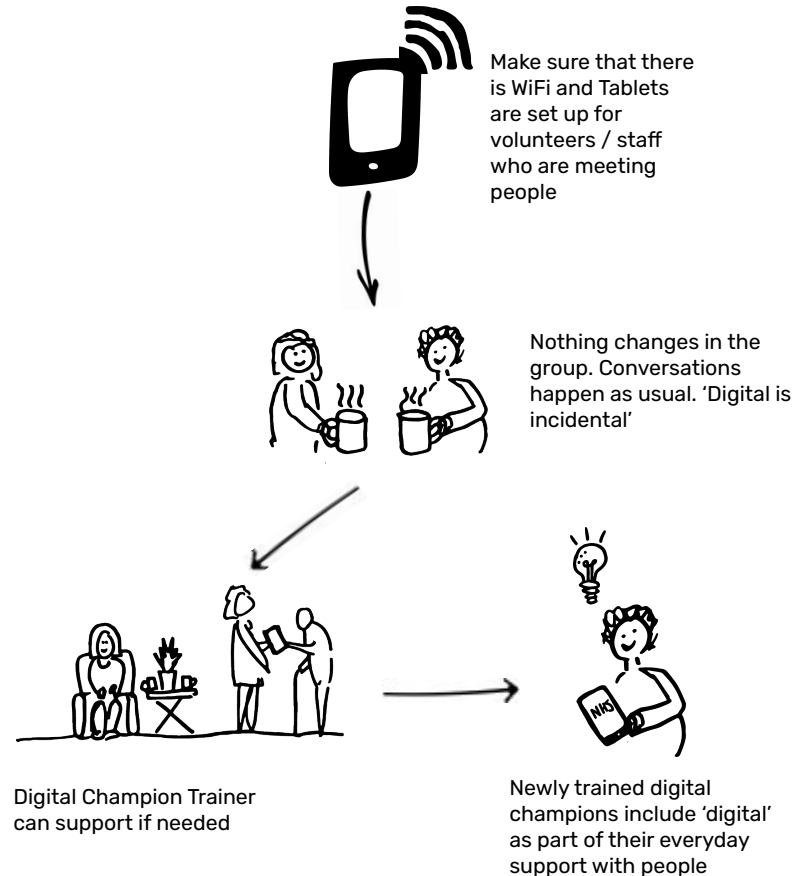
Self Help UK (who are implementing these changes in this pathfinder) "meet people where they feel most comfortable". This means that they need municipal access to hardware so that they can support people no matter where they are

Note: Tablets offer greater usability for people who may have dexterity issues. We suggest a small number of cheap tablets first with a few volunteers who are most enthusiastic about the programme.

Support

Your Digital Champion Trainer can support initial sessions (but remember that parachuting someone new into a relationship isn't ideal for creating an 'incidentally digital' programme)

See **Stage 3** for tips and ideas of what to try first



STAGE 3: Support

Closed Facebook Groups (Notts County F.C Support Group)

We know that a big need for people living with (and beyond) cancer is the timeliness of emotional and practical support.

“I need support when I need support, not one week from now”

We have found through a number of pathfinders that using closed facebook groups accessed by people with specific conditions can give support at the time that it is needed.

At first it is through the emotional support of peers who are having similar experiences. Replies to comments are usually quick and can help with immediate needs.

Ideally the same group can be accessed by a Health Professional who can help with acute medical queries.

Placing support on a platform (such as facebook) where people already access means it becomes part of the norm, they don't have to platform shift (to a cancer specific site) and are more likely to be on it to support others.

See our full guide to Facebook groups for Long Term Conditions [here](#)



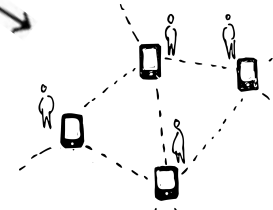
A community organisation creates a closed facebook group for people with cancer



People are sign posted to it by health professionals and community volunteers



People get timely emotional and practical support from their peers



People are more likely to feel supported and therefore willing to support others

STAGE 3: Support

People you need

Digital Champions Trainer to set up the Facebook group in the first instance

Digital Champions from a community asset to help facilitate the group (in this case it was Notts County FC Support Group)

People with lived experience to be part of the group

Health Professionals to signpost people to the group and to join it if possible

Resources you need

Group rules a note on what the group is for and some house rules

Resources to point people to periodically. E.g. what's on, useful apps

STAGE 3: Support

Don't:

- Think that everyone will want to join. This isn't mandatory.
- Worry about the potential of negative comments in the group.

It is their group and should be open to this (we have found that groups are self policing and overwhelmingly positive)

Do:

- Have an active Digital Champion within the group - at least in the beginning so it gets some momentum
- Encourage members to meet up in person as well as online if appropriate

Don't:

- Make this a virtual clinic. This is not the space for medical advice
- Think it takes a lot of time to facilitate a group (facilitators can effectively manage a group with 30 minutes dedicated time per week)

Do:

- Encourage people to give life hacks
- Encourage Health Professionals to be involved or sign post to it

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Provide initial list of things to try and be built on locally

STAGE 3: Try This

The list is meant to be a conversation starter. It should not be formal and it should take into account

- 1) Local services provision
- 2) The fact that people will have their own preferences that won't be on the list (as long as those preferences are safe and trusted then go with them)

For more experienced Digital Champions this will be a timely reminder of some of the things they can explore with people. For those who are new to the Digital Champion role it gives a good starting point for discussion.

Opposite are a couple of examples from the list in the Nottingham Pathfinder

Trusted services:

[NHS.uk](#), [Macmillan](#), [Self Help UK](#), [Maggies](#), [HealthUnlocked](#)

Everyday:

Supermarket delivery (Groceries etc.), [Maps](#), Social media (whichever platform they may prefer)

Apps

NHS App, [NHS Apps library](#) (people might be in need of things other than Cancer apps e.g. mental health apps)

Enjoyable

[Youtube](#), iplayer, favourite hobby websites

STAGE 3: Try This

People you need

Digital Champions from a community asset who already have conversations with people and can update the list

Clinicians to review the list periodically and provide advice on its content

Resources you need

Tablets to take to people's homes (or wherever they feel most comfortable meeting)

Electronic doc with shared access to start your list off

STAGE 3: Try This

Don't:

- Think this is a definitive document. It will change over time

Do:

- Grant access and share across your digital champions and health professionals

Don't:

- Treat it as a formal document. It is just a conversation starter with some ideas on it

Do:

- Feel empowered to add things (if they come up a lot with people - and are safe) and delete things that are no longer relevant

In your area

This is how we did it in Nottingham. We have tried to make the model as flexible as possible allowing for local context and local needs

To embed this into another area we recommend;

- Bringing together as many Cancer groups as possible
- Training digital champions who already spend time with people with Cancer

If you would like to discuss how you might be able to try something in your area please contact pete@goodthingsfoundation.org

Assets

Design Workshop - [stakeholders](#)

Design Workshop - [users](#)

Design Workshop - [template](#)

Digital Champions [recruitment session](#)

[Facebook group evidence](#) from other pathfinders