

# Nottingham Pathfinder: lessons learned

Using digital to support people  
on their cancer journey



# Introduction

**“cancer can turn your world upside down. But you are still you: mums, dads, friends, lovers, work mates and more.”**

([Macmillan website](#) 2020)

The Nottinghamshire Pathfinder aimed to support people with or recovering from cancer, to see whether using digital might help them feel supported, improve their access to peer support, and get up-to-date information and health professionals.

Following time spent talking to front line staff, running workshops with local stakeholders and doing user research with people who have a cancer diagnosis, we identified three recommendations. These were suggested because they were relatively fast and low-cost ways to improve the service used by people with a cancer diagnosis.

Connected Nottinghamshire then began to test out these recommendations through a range of activities and partnerships:

1. Maggie’s Centre
2. Football in the Community – Cancer and Rehabilitation Exercise (CARE)
3. Self Help UK – Beyond Cancer Diagnosis Team
4. Social Prescribing – Link Workers

# Intervention model

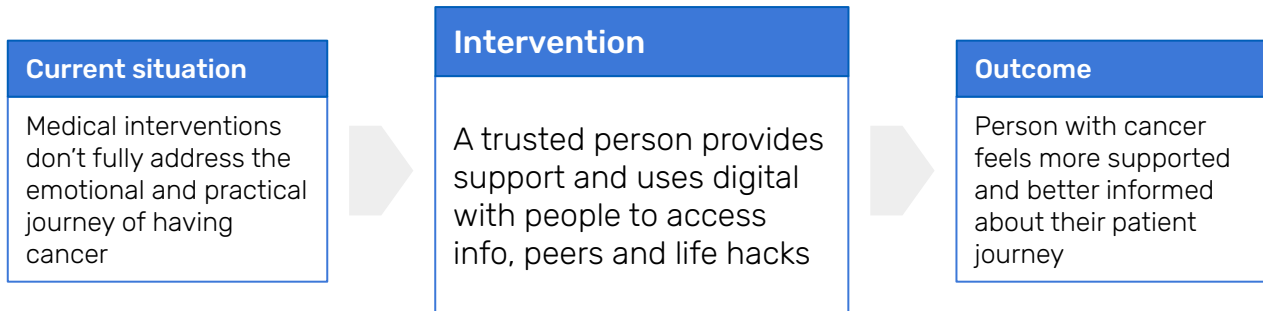
We know that there are medical, emotional and practical things to consider when someone has been diagnosed with cancer.

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.

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

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



# Pathfinder reach and impact

<  CARE Group (Nottin...  

## Digital Support Hub at Nottingham Central Library

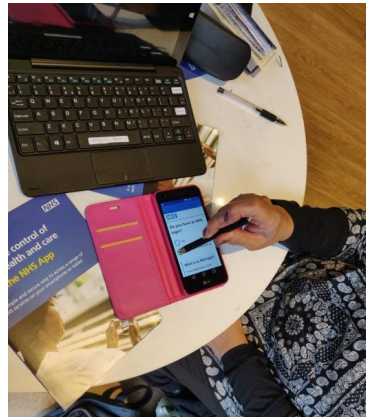
Free training and support to keep in touch with family and friends, enhance your hobbies, take an active role in your health and wellbeing and much, much more.

A Digital Support Hub is now available at Nottingham Central Library. A welcoming space where... See more



 2 others

Seen by 41



Stakeholders engaged 298

People supported in-depth 263

Digital Champions trained 11

# Maggie's Centre

Maggie's Centres offer free practical, emotional and social support to people with cancer and their families and friends. Based on a design workshop and user research, a recommendation was given to work with a Maggie's Centre to support people who lack digital confidence, to look for health information and tools online – providing the centre with 3-4 tablets preloaded with digital health tools and Information.

We tested Digital Support drop in sessions during September with Maggie's Nottingham, based within Nottingham City Hospital campus. A member of staff from Connected Nottinghamshire was present to support people with using technology, focusing on whatever matters to the individual. Tablet devices were available for visitors to use.

Each Maggie's Centre has a clear and defined model of care and support, for which 1:1 direct conversation with support specialists and centre staff, as well as group sessions are used. There is a timetable with free groups, classes and workshops. Sometimes, well established approaches can understandably result in reluctance to innovate.

## **Lessons learned**

Over the three weeks it became apparent that people were visiting the centre to attend a regular, timetabled group held upstairs. This meant it was difficult to engage with the number of people who came through the doors as they would 'come and leave'.

We used the kitchen/dining area (the hub of the centre where people meet) to engage with people about how technology could support their health and care. Although people were interested in talking about this, only a few actually used the tablets. Most had no interest as they came to the centre for social interaction.

Learning from this, we made suggestions around the possibility of holding a scheduled digital support session within the timetabled plan, for those who wanted to attend a specific group to gain digital skills and confidence. The Centre suggested including a short slot within their 'Welcome to Maggie's' introduction session.

# Case Study 1: Benefiting from Digital Drop-Ins

In one of the Maggie's Centres, we met a lady recently recovering from cancer. She was one of the **74 individuals** that engaged with the digital support drop in sessions at the centre. She told us her limited experience using digital technology and lack of access to broadband at home so the team started with showing her some basic skills such as smartphone touchscreen functionalities. She was very enthusiastic about improving her digital skills, particularly to use a tablet she **"bought a few years back, but could never use"**. As she continued to regularly attend the drop in sessions the team were able to build a relationship with her. She described how she had lost her confidence: **"when you've had a change in health circumstances, it impacts on your motivation ... the sessions have really supported me and is giving me something different and new to look forward to."**

We directed the lady to the Digital Support Hub at Nottingham Central Library to continue developing her skills outside of the digital drop in sessions at Maggie's Centre. She regularly attends and has continued to develop her digital skills which are supporting her health and overall wellbeing. She can now use the NHS App to access her GP record: **"the pathfinder helped me look up trusted websites to get a better understanding of some of my medication."**

Because of her improved confidence and access to trusted support, she was able to take the next step on her digital journey, she felt able to improve her access to the internet in her own home. **"I never thought I'd be where I am now, getting a data package and upgrading my contract so I can use my phone and internet more at home wouldn't have been possible without help from the digital support sessions."**

# Self Help UK - Beyond Cancer Diagnosis Team

Self Help UK and Macmillan Cancer Support run the Beyond Cancer Diagnosis Service. They provide practical and emotional support to people affected by cancer, delivered by a team of specially trained volunteers. One of our user research findings was that people, at a certain point, fall off the end of the 'hospital system'. Finding places for emotional support really matters, so it is important that these places are digitally confident and have digital champions.

The recommendation we wanted to explore was a Beyond Cancer Diagnosis Service – Digital Champions Network.

Requirement scoping took place and it was agreed 10 people would be recruited to work with patients and carers, skilling up on digital use such as online shopping, safe internet searching for medical issues, connectivity to friends and family and support platforms. This involved: 6 Digital Champion volunteers, 3 Digital Champion workers, 1 Deaf Digital Champion volunteer. Each of the 10 digital champions would be provided with a tablet through a lending scheme so they had the tools they need to support patients.

## Lessons learned

It can take a significant amount of time to get confirmations of commitment in place. Requirements gathering started in September 2019; agreement to progress was received in December 2019. This mainly reflects capacity issues.

In future, other areas this service wants to explore are:

- Closed Facebook groups for cancer self-help groups, managed by trained volunteers.
- Piloting electronic Holistic Needs Assessments with patients, providing staff/volunteers with tools to undertake these in people's homes.
- Digital inclusion workshops at another Self-Help UK base, so patients can get the digital help they need.

# Case study 2: Being a Digital Champion

The best way for those living with, and beyond a cancer diagnosis to benefit from digital is to work with those already supporting people. This is why we linked up with Self Help UK – Beyond Diagnosis Service.

We recruited volunteers who were passionate about championing digital services through emails and face to face contact. Eleven people came forward – one was Martin. He told us: **“my IT skills are fairly basic, I have never used a tablet for example” but “being a Digital Champion I hope to improve my knowledge and skills around IT and techniques so I can better support the people I help – if I can do it, they might be able to too.”**

The service also had a support group which offers help for deaf service users; **“research has shown that deaf cancer service users are very isolated and there isn’t much support for them.”**

So we made it a priority to ensure some of the services deaf volunteers were also recruited. **Amongst the eleven, six of the digital champions were deaf volunteers.**

The service explained to us that one of the biggest ways they help people is through reducing isolation, as social inclusion has been a significant factor for service user’s improved health and wellbeing. The volunteers support people in the places that are best for the person; they go to their houses to spend time with them or meet somewhere such as a coffee shop. So an important part of our training to the digital champions was to include ‘Keeping in contact’, by including content about the different peer support groups’ online and video calling tools.

Martin was particularly enthusiastic about this section of the Digital Champion training because **“it will increase the independence and self-esteem of individuals living with cancer, they will be enabled to access support and keep connected outside of the face to face meet-ups.”**



# Football in the Community - CARE programme

Football in the Community – Cancer and Rehabilitation Exercise (CARE) programme uses physical activity to help patients in recovery. They provide a social environment to share stories, build strength and self-esteem. One recommendation from design workshops was to set up a closed Facebook group for peer activity, emotional support, sharing of electronic leaflets and advice on online tools/ information. We began to work with the FITC CARE programme as they already had a closed Facebook group, run by users of the service. We piloted:

- Roll out of an iPad/ Tablet lending scheme so members of the FITC team could create exercise video content for uploading onto the programme's closed Facebook group or website..
- Making iPad/Tablets available in the social time following circuit sessions (alongside other leisure centre facilities including the gym, badminton courts and swimming pool).
- Explore embedding a Digital Support Hub at Portland Leisure Centre for Football in the Community's Cancer and Rehabilitation Exercise (CARE) programme.

## Lessons learned

We tested our suggestions at two of the circuit training sessions during November.

- FITC CARE programme has a clear and defined model of care and support. When visiting the programme we were given a slot to inform people of the pathfinder. Service users were then given the option of using their 30 minute social time to use the facilities or speak with us about digital. We found that most people wanted to spend their time keeping active.
- Conversations were held several times with the CARE Coordinators around the possibility of rolling out an iPad/ Tablet lending scheme. Initial enthusiasm petered out.

# Case study 3: A safe place to share

Football in the Community's, Cancer and Rehabilitation Exercise (CARE) programme provides cancer patients with the chance to attend exercise classes to help them throughout their journey. The service has supported over 220 people to increase their confidence. The Project Coordinator explains: **"the project gets people active but outside the sessions, online peer support was a gap that needed filling."** This is when the creation of the closed CARE Facebook group emerged; people needed a **"safe place to share stories and information"**. Where members could actively post personal health and thoughts; exercise information and achievements, a place for encouragement through peer support, photos and humour.

Tony, a long standing member of the CARE programme, told us: **"When you have cancer, you're often living in a confusing 'fog', 'Chemo brain'. Not knowing what to do and where to turn for information and guidance. Simple, clear and easy to find information is extremely important for cancer sufferer's physical and mental wellbeing."**

Tony was vital in creating and championing the use of the group, because "there were a limited amount of online peer support groups available out there and they're not always easy to find." Tony went on to tell us how essential he felt it was that people have access to health services, information and peer support on the internet.

**"One of the most important things the CARE Facebook group has done for me is helped me build a tight social network of like-minded 'CanLivers' who meet, communicate, share concerns, troubles, successes, advice and overall promote mental wellbeing."**

The Facebook Group is only viewable to CARE members and selected CARE Coordinators. There are currently 63 members who are a part of the group; who receive specialist advice and updates about the CARE project from the Project Co-ordinator, and use it as a platform for encouragement and social interaction.

# Social Prescribing Link Workers

Social prescribing empowers people to take control of their health and wellbeing through referral to non-medical Link workers.

Link workers give people time and focus on what matters to the person, as identified through personalised care and support planning.

There is a team of 29 Social Prescribing – Link Workers in Nottinghamshire’s ICS.

The aim is to pilot a model with the team by initially providing Digital Champion training and devices to all workers so they are able to support people more effectively.

## **Lessons learned**

The Social Prescribing – Link Worker team has only recently come into place within Nottinghamshire. As the team is new, they’re establishing new ways of working and setting their own department objectives.

## **What next**

The plan is for Link Workers to be able to support those with a cancer diagnosis feel more connected through direct social prescribing to a Digital and Social Inclusion Project, which will look to;

- Provide people with assistive technology; devices and technologies which help people to stay safe and self-manage
- Signpost people to Digital Support Hubs for skills training

