Using closed Facebook groups for people with Long Term Conditions

A How To Guide for digital inclusion in health

August 2018

Good Things
Foundation

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Introduction

The Stoke Pathfinder was set up to investigate ways that digital can benefit patients with Long Term Conditions. This guide is one of the models that worked well - creating condition specific closed Facebook groups

Having a Long Term Condition can feel very isolating and it is often difficult to find support and/or useful information at the exact time that you need it.
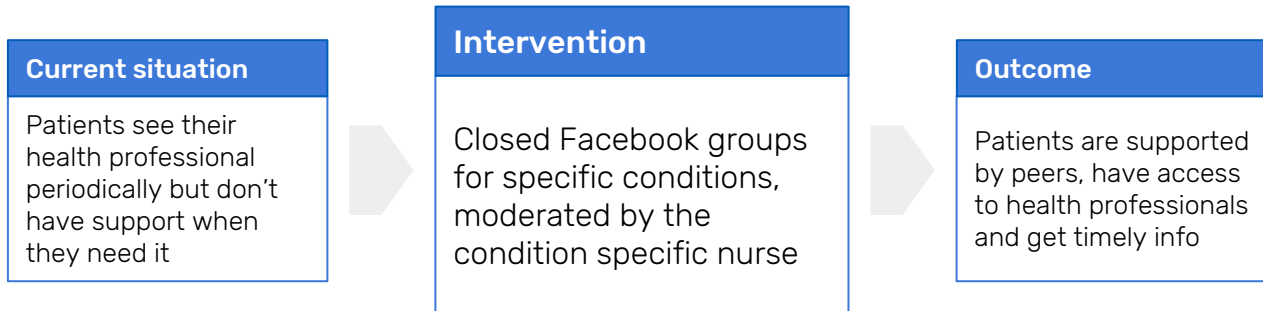
Currently there is a tendency, upon diagnosis, to give all possible information to patients about their condition, what to expect and even how it may deteriorate. We have found that this information is not used by patients in a positive way. Patients need pertinent information to them - at the point when they feel they need it.

Peer support is very valuable in the emotional journey of patients with a Long Term Condition. Access to conversations- on a platform or place - that you already are is a valuable resource.
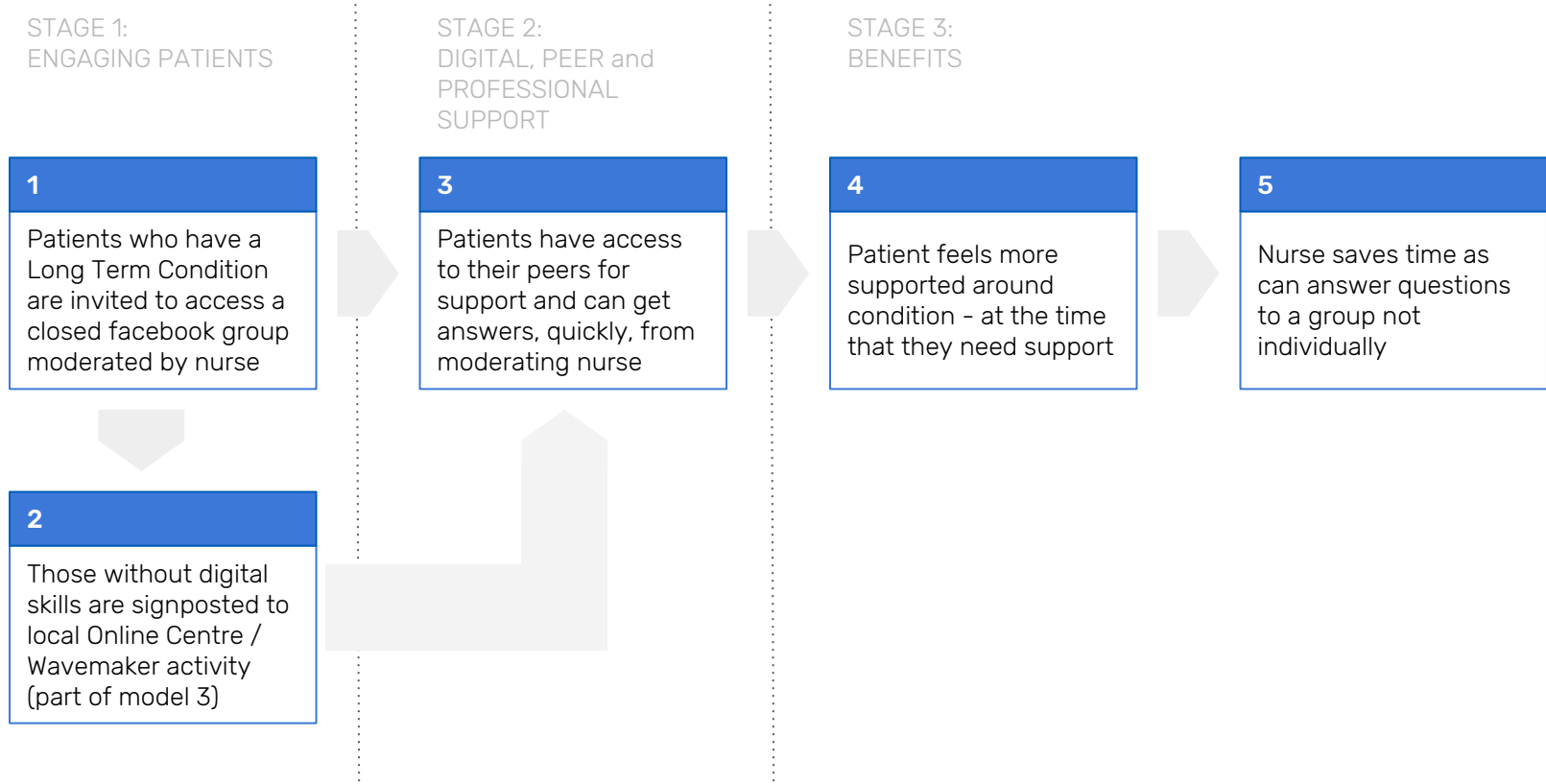
Aslo having a captive audience for health professionals to answer questions once and drip feed guidance.

We used closed Facebook groups to satisfy these needs for patients. The recommendations within this guide are based on a 12 month Pathfinder project in Stoke.

Current situation	Intervention	Outcome
Patients see their health professional periodically but don't have support when they need it	Closed Facebook groups for specific conditions, moderated by the condition specific nurse	Patients are supported by peers, have access to health professionals and get timely info

Intervention model

Model 1: Condition specific closed facebook groups for those with Long Term Conditions

STAGE 1:
ENGAGING PATIENTS

STAGE 2:
DIGITAL, PEER and
PROFESSIONAL
SUPPORT

STAGE 3:
BENEFITS

1

Patients who have a
Long Term Condition
are invited to access a
closed facebook group
moderated by nurse

3

Patients have access
to their peers for
support and can get
answers, quickly, from
moderating nurse

4

Patient feels more
supported around
condition - at the time
that they need support

5

Nurse saves time as
can answer questions
to a group not
individually

2

Those without digital
skills are signposted to
local Online Centre /
Wavemaker activity
(part of model 3)

Before you start

We appreciate that there will be initial concerns about using condition specific closed Facebook groups. Firstly, check your organisational social media policy e.g. NHS Confed

It is important to set out the rules for the group and its purpose. Something like;

"This is a safe area to support each other through your journey navigating XXXXXXXXXXX. Please do not give medical advice - we've got that covered. Chat to each other and let's help each other in any way we can. We will post information on here from time to time and try and answer some queries."

There is some helpful guidance from Redmoor Health here

Then choose the nurse that will be moderating the group to set it up and put on a couple of informative pieces to get it started - digitised leaflets, videos or guides that might help.

The nurse will need to know what support is available locally for those who don't have digital skills. Have a look at the Online Centre Network for ideas on what organisations might be close by.

Check local governance rules

Decide what you want the rules to be and the group's purpose

Set up a closed Facebook group for a specific condition
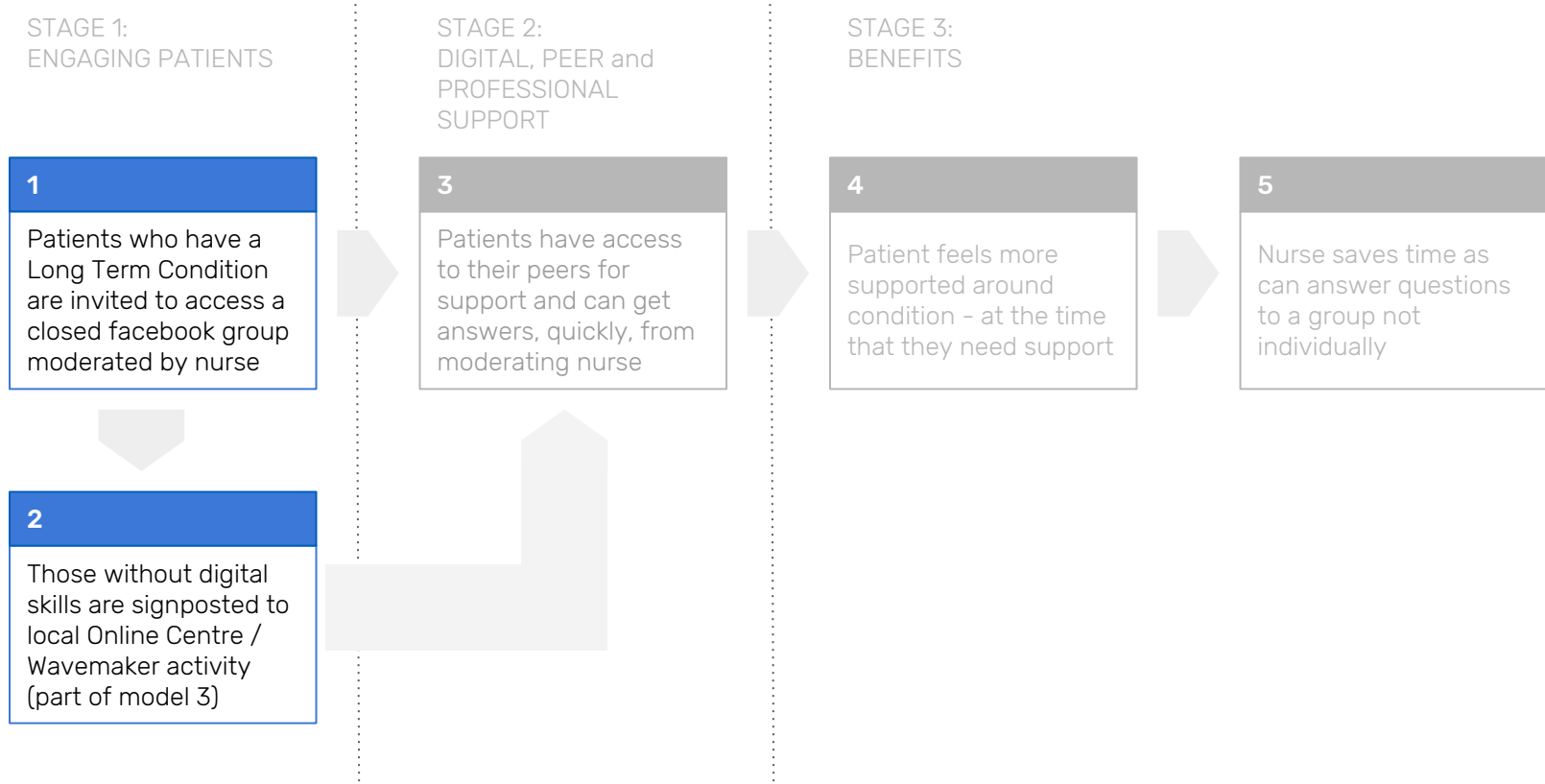
Populate it with some useful information

Find a local community centre that does digital skills

Intervention model - Engaging Patients

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Patients have access to their peers for support and can get answers, quickly, from moderating nurse

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Patient feels more supported around condition – at the time that they need support

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Nurse saves time as can answer questions to a group not individually

STAGE 1: Engaging Patients

Having set up the closed Facebook group it is now time to get patients involved.

Build in the advertising of the group at the end of 'check ups' - not after an episode. This might be an annual review, monthly levels reading - all depends on the condition and local care paths.

Explain the purpose and rules of the groups and discuss the value that patients and staff are getting from it.

Use a tablet or smartphone to physically show the group and show how vibrant it is.

For those who do not have the digital skills to use this it will be a longer process. Sign post those individuals to a local Online Centre and then if they take that up start the Facebook conversation again next time.

At the end of scheduled check up Nurse talks about the closed Facebook group.

Physically shows the group to the patient

Patient doesn't have the skills to access the group

Patient becomes part of the group

Signposted to an online centre to learn digital skills

STAGE 1: Engaging Patients

People who are needed (not exhaustive)

Condition Specific Nurse who can set up and moderate the group, answer queries and upload relevant content.

Consultant to buy in and promote the group at their appointments. Also to add comments when necessary within the group itself

A senior sponsor within the hospital who understands the value and can help navigate the layers of governance in the locality

Patients who are early adopters. This will help get activity on the group in the first instance

Patients who are sceptical to help inform what would be useful and to help improve the community.

Local Online Centre contact to be able to sign post those who aren't confident in their digital skills

Resources that are needed

Documented governance on what the purpose and rules of the group are

Ring fenced time for Nurse to set up the group and monitor activity/answer queries etc. This investment in time has shown to reduce other query management by up to 30%

A tablet or smartphone to show the closed group to the patient

A local Online centre relationship to signpost people who aren't digitally confident

Assets to upload e.g. video content, digitised leaflets, list of websites that might be helpful

STAGE 1: Engaging Patients

Don't:

- Think of the governance structures as something to 'get through'. They are there to keep everyone safe. Work with them to find a way forward
- Think that the facebook group replaces face to face. It is simply a mechanism for support during non clinical hours - at the convenience of the patient

Do:

- Detail hours that you will be trying to monitor the group in order to manage expectations.
- Remain human. Patients respond better to personality than formulaic responses
- Talk about the challenges you are facing (internal and external). This provides great learning for your colleagues if they decide to take it up for another Long Term Condition
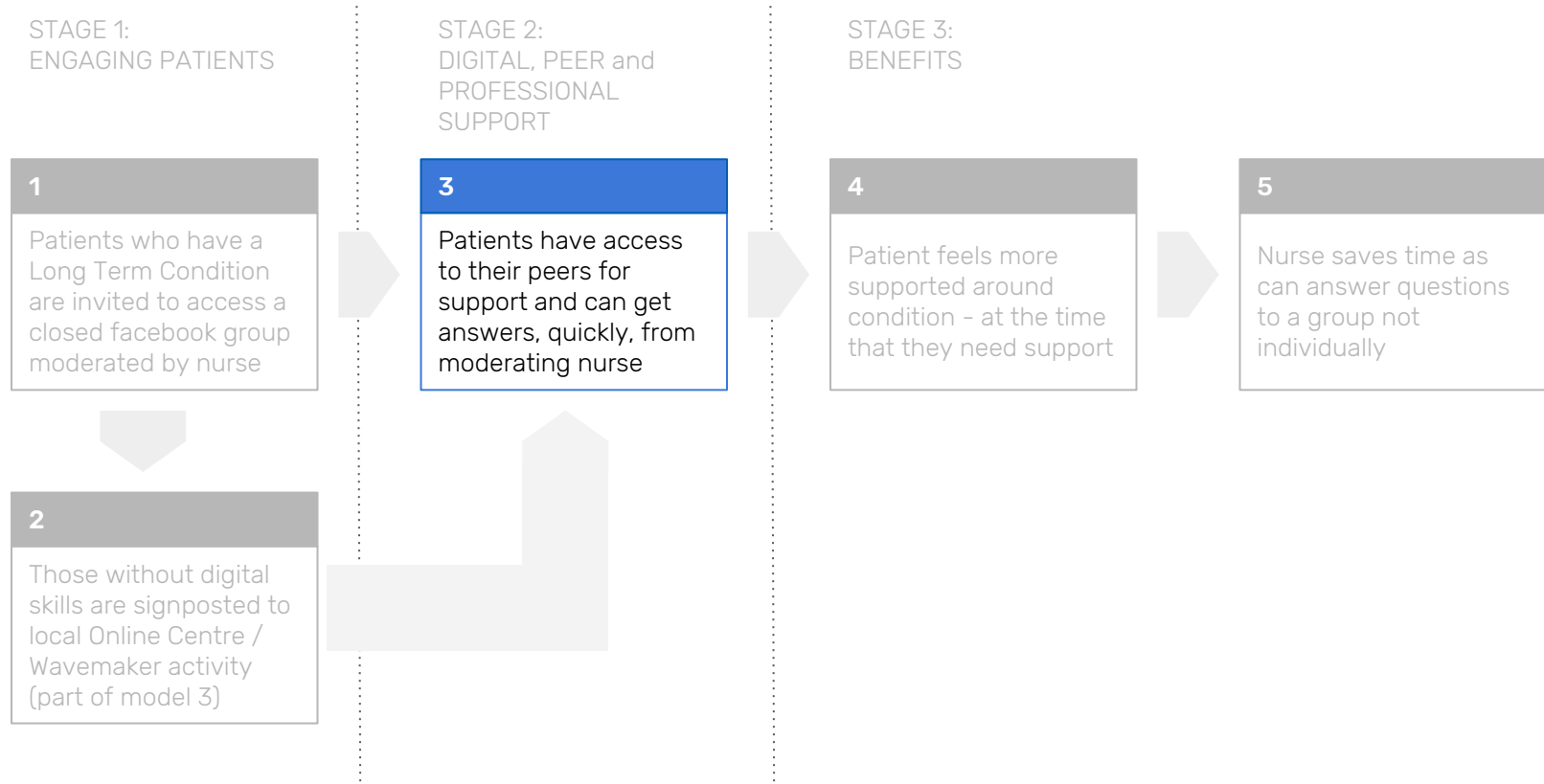
Don't:

- Think that this will be perfect on day one. YOu are building a community and this takes time. Tell patients this and value their feedback
- Think that negative comments are universally felt. Acknowledge them and ask for genuine ideas to take forward from your group.

Do:

- Start small and seek constant feedback on what could be done to make it better.
- Create posters etc of frequently asked questions. You can display to all group members then instead of answering single queries about the same thing.
- Talk to patients about how they might be able to help others, this group is a mutually beneficial space. It shouldn't just be one way.

Intervention model - Digital, Peer and Professional Support

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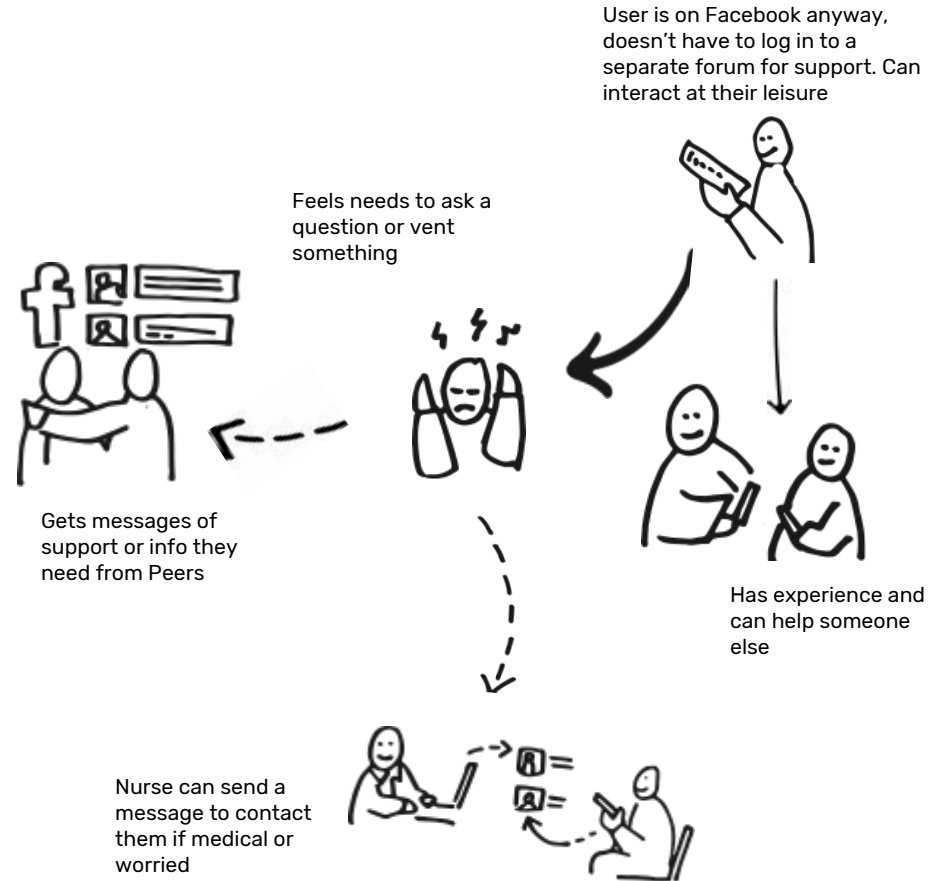
STAGE 2: Digital, Peer and Professional Support

How this level of support is described for patients is important. 'Digital' only facilitates access to peers (often working best because someone can help at the exact point a patient needs it) and professionals (by passes the usual mechanisms like calling or waiting for an ad hoc appointment that was inappropriate.)

As such Nurses and patients will never have need to use the word 'digital'. It is not well defined and ultimately leads to confusion. Simply talk about how there is support here on Facebook.

The peer support is vital in this model. Patients trust their peers as they understand what they are going through in a way that health professionals and even family can't. Encouraging 'life hacks' ("XXXX holidays give free insurance for people with XXXXX condition") as well as the emotional support ("I remember when I felt like that, we are here to talk if you need us") are equally valuable in maintaining activity in the group.

User is on Facebook anyway, doesn't have to log in to a separate forum for support. Can interact at their leisure

Feels needs to ask a question or vent something

Gets messages of support or info they need from Peers

Has experience and can help someone else

Nurse can send a message to contact them if medical or worried

STAGE 2: Digital, Peer and Professional Support

People who are needed

Condition Specific Nurse with ring fenced time to moderate the group, answer queries and upload relevant content

Wider condition specific nursing team buy in to promote the group at their appointments

Patients to sign up to the group and be active

Local Online Centre contact to be able to sign post those who aren't confident in their digital skills

Resources that are needed

Capturing FAQ's and being able to create (find already created) materials to post onto the group

A tablet or smartphone to show the closed group to the patient.

A growing bank of materials that can be re posted if needed.

STAGE 2: Digital, Peer and Professional Support

Don't:

- Rule with an iron fist. Yes, be firm if people are giving out health information when they shouldn't but allow people to vent and remain positive
- Show the group using a PC, this can make it look like more kit is needed for the patient. Using the devices that a patient uses (tablet/smartphone) is more inclusive

Do:

- Encourage those supporting others, even when it seems silly. Conversations will go off on tangents but that's still emotionally supporting
- Remember that this is a rich, and continual, source of patient insight into what is useful and when it is needed in their journey
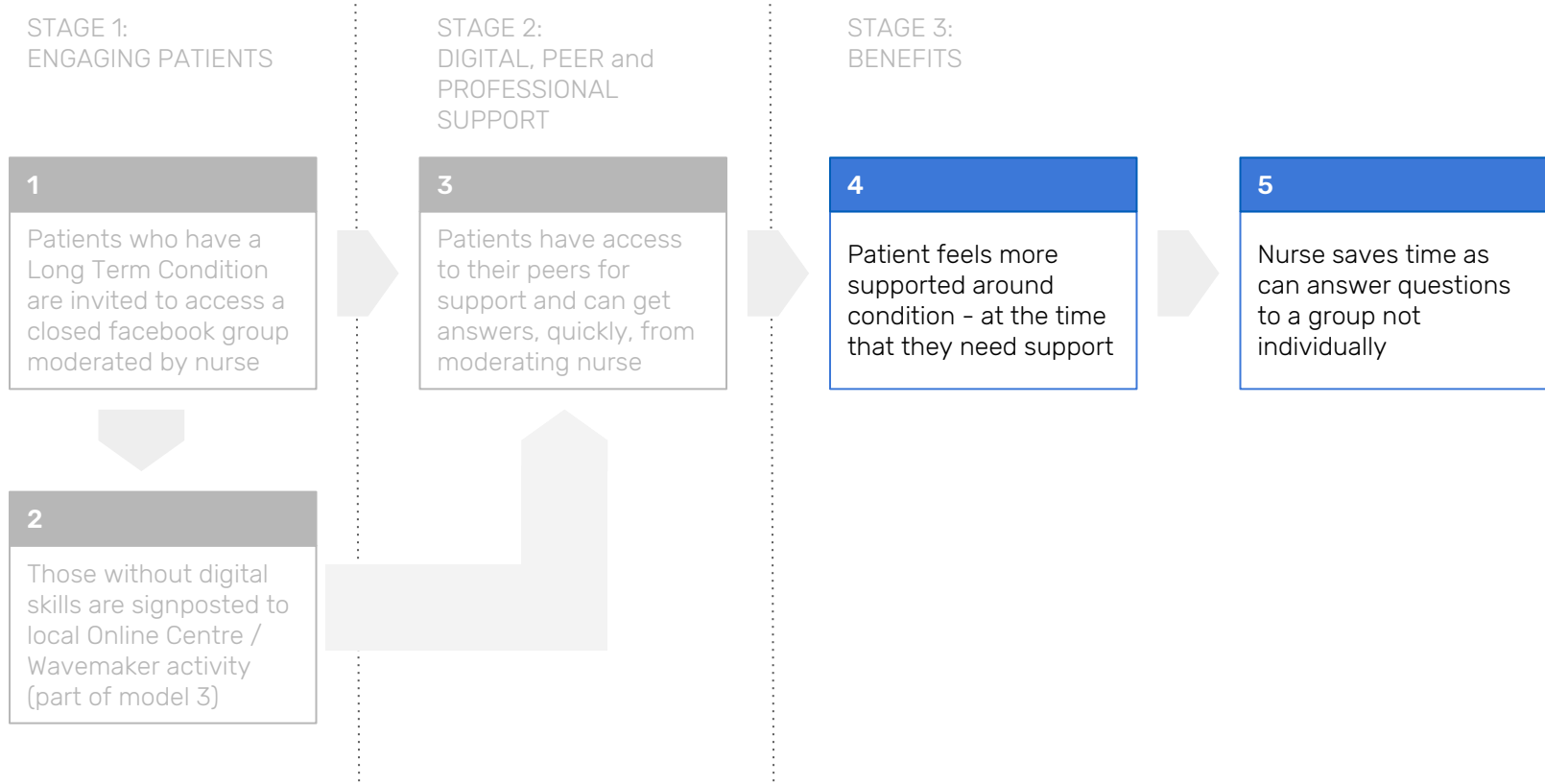
Don't:

- Allow medical advice to be posted by peers. Encourage emotional support and life hacks. It is important to not rule with an iron fist but constructively say that medical advice is for medical staff
- Think that this will be the only source of support/advice that patients will be using. Encourage (trusted) websites/material

Do:

- Remember that just because a video/leaflet has been posted once doesn't mean everyone got use out of it at that point. Be prepared to repost if necessary
- Talk to other colleagues about the the benefits of the group and how to overcome hurdles
- Get a Senior Sponsor to reflect on how the group is going - bring the moderating Nurse into steering meetings to show other departments the progress

Intervention model - Benefits

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STAGE 3: Benefits

We have a conducted a 'realist evaluation' of this model here.

The benefits for this work fall into broad categories

Customer Service

- Patients feel that this is an improved service from their NHS. This is due to easier access to health professionals and peers and also the convenience of it being on the same platform that they naturally gravitate toward

Wellbeing / emotional support

- Being able to talk to peers who understand their condition and context (locally and medically) gives a sense of community resilience and activation

Health professionals

- An avenue to get important information to patients with more chance that they will digest it and act upon it
- Saving of time for answering queries by telephone, email or ad hoc appointments

Customer service	Wellbeing / emotional support	Health professionals

It takes less time to find out what I need to know at the point I need to know it

I can just say I'm feeling rubbish because of XYZ and I get support/advice

I can answer queries just once and this means I can spend more time with patients

This is a better service from the NHS

I like helping others in the same position as me

I'm closer to my patients and I know more about their lives

STAGE 3: Benefits

Don't:

- Think that you need to be a digital expert to do this. Technical ability won't determine the success of this - this is just another avenue to supplement the incredible human service you already provide

Do:

- Bring your personality to this. Patients feel supported when they are listened to and acknowledged, not when they feel like they are in the mechanisms of the NHS and going through the motions

Don't:

- Think that benefits are universal for all users, they are on a spectrum - this pathfinder had overwhelmingly positive experiences

Do:

- Capture as much insight as possible and share it - good, bad and what you have changed are all important
- Flex and change the model as necessary. Local context is important and you know your context better than anyone.

In your area

This is how we did it in Stoke for the following Long Term Conditions;

Atrial Fibrillation

COPD

Asthma

Multiple Sclerosis

We have tried to make the model as flexible as possible allowing for local context and specific condition needs.

To embed this into another area we recommend;

- Finding a Senior Sponsor for the activity - a consultant who is bought in adds substantial value.
- A Nurse that feels confident in digital to head up the first group

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

Assets

[Evaluation](#)

[Design Workshop 1](#) - Stakeholders

[Design Workshop 2](#) - User Insight

[Alpha evaluation](#)

[Closed facebook in-depth guidance](#) - Redmoor Health

[Case Studies](#) and [video](#)

[Online Centre Network](#)

[Blog on peer trust](#) through social media

[Redmoor Health](#)

[Wavemaker](#)

[Setting up a closed group on Facebook](#) video - Redmoor Health