

SIGN: Evaluation of the SIGN Patient Decision toolkit on long-term effects of COVID- 19

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Contents

Background	2
Methods	4
Results	5
Conclusion.....	12
Acknowledgements	13
Appendix: Questionnaire	14

Background

Healthcare Improvement Scotland (HIS) aims to enable the people of Scotland to experience the best quality of health and social care. The Evidence Directorate, within Healthcare Improvement Scotland, has eight goals as illustrated in *Figure 1*.

Figure 1: Healthcare Improvement Scotland's Evidence Directorate Strategy

We have 8 shared goals across the directorate:



The Scottish Intercollegiate Guidelines Network (SIGN) team within the Evidence Directorate works with health and social care professionals, members of the public, patients and people with lived experience, and other stakeholders to develop national evidence-based clinical guidelines. These guidelines use the latest clinical evidence and make recommendations to reduce unwarranted variation in practice and improve clinical care for patients across Scotland. Each guideline has an accompanying public version which is available from the SIGN website (www.sign.ac.uk/). Since 2007, the format of public versions of guidelines has been PDF. As part of the Evidence Directorate goals to 'develop outputs that meet the needs of our stakeholders' and 'invest in digital technology to improve efficiency & effectiveness of our work', SIGN produced other formats for public versions of guidelines including video. More recently, SIGN collaborated with the Digital Health & Care Innovation Centre (DHI) to develop a digital tool for people with long COVID. The aim of the tool was to help them access up-to-date treatment advice and record symptoms that can be shared with their GP.

The DHI Centre leads delivery of the national decision support programme 'the Right Decision Service'. This service is used by teams across Scotland to develop their own decision-support platforms to share information, guidance documents and tools to support decision making. It can be accessed as a website (<https://rightdecision.scot.nhs.uk>) and mobile application (app).

To date, SIGN has produced five digital toolkits aimed at healthcare professionals to support the use of guidance and guidelines and one digital toolkit for patients and the public. The toolkit 'Managing the long-term effects of COVID-19' for patients and the public was a pilot and the aim was to evaluate its value with people with lived experience of long COVID.

The SIGN Patient Decision Support platform is an app and accompanying website which provides access to SIGN Patient Decision Support toolkits based on SIGN guidance. The 'Managing the long-term effects of COVID-19' toolkit can be found on the website [SIGN Patient Information \(signpatientdecisionsupport.uk\)](https://signpatientdecisionsupport.uk) and within the 'SIGN Patient Decision Support' app which can be downloaded from the App store and Play store and for use on iPhone, iPad, iPod Touch and Android phones and tablets.

The SIGN Patient Decision Support toolkit for 'Managing the long-term effects of COVID-19' includes information from the SIGN booklet on 'Long COVID' which itself is based on the SIGN guideline on '[Managing long-term effects of COVID-19](#)'. The toolkit includes an interactive symptom diary, allowing users to track symptoms and record progress.

The objectives of this evaluation were to:

- summarise feedback from app users
- make recommendations about updating of the current toolkit
- make recommendations about whether digital toolkits should be developed for patients and the public in the near future.

Methods

Quantitative data collection

Quantitative data were collected and analysed to determine the reach and usage of the app and toolkit, this included the number of:

- downloads of the Decision Support iOS app from App Store
- engagement recorded on the Decision Support iOS app
- downloads of the Decision Support app from the Google Play store
- engagement recorded on Decision Support Android app
- number of views and number of users recorded for the Decision Support toolkit

Qualitative data collection

We invited people with experience of long COVID, and who have used the app, to provide feedback through an online questionnaire and telephone questionnaire.

The opportunity to participate was advertised through Long Covid Scotland, SIGN's Patient and Public Involvement Network (which includes third sector organisations) and social media.

A total of 11 people provided feedback, six completed the online questionnaire and five completed the telephone questionnaire. The telephone questionnaire was conducted by SIGN's Patient Involvement Advisor. Although the small number of people who provided feedback means results cannot be generalised to all users, it does give insight into people's experiences of using the app and potential areas for improvements

General feedback from other sources such as emails sent via Long Covid Scotland, Tactuum (product developer) and DHI has also been included in this evaluation.

Results

Usage of the SIGN Patient Decision Support toolkit on 'Managing the long-term effects of COVID-19'

The estimated download number for the SIGN Patient Decision Support toolkit on 'Managing the long-term effects of COVID-19' between January 2022 and November 2022 was 2,043 (246 on iOS App store, 129 on Google Play store and 1,668 on the web version). From January 2022 to November 2022, the number of users engaged was 14 per day.

Feedback SIGN Patient Decision Support toolkit on 'Managing the long-term effects of COVID-19'

All people testing the toolkit had direct experience of long COVID and were using the app version of the toolkit.

To gain an understanding of how useable the app is with users, participants were asked questions on findability of information, functionality, navigation and design. Questions on usefulness of the app were asked, including their impression of the app, quantity of information provided and benefits of the app.

Findability of information

People who provided feedback found it easy to find information on the app and found the symptom diary particularly useful for recording and sharing information with their GP.

How easy was it to find information on what will happen at assessment?

10 out of 11 users who provided feedback found it very easy to find this information. Comments included:

"Wasn't a difficulty but thought it might be easier to link back from the two sections."

Can you find information on things people can do to help themselves?

All respondents could find this information and found it very easy to find.

Comments included:

"Quite obvious."

"This part really helpful."

"I was interested in this. That's what we want, information so we can help ourselves. Here it's all in the one place."

Can you find information on what will be discussed with you when developing and agreeing your rehabilitation and management plan?

All users who provided feedback found this information.

How easy was it to find the information?	Number of respondents	Percentage of respondents (%)
Very easy	8	73
Quite easy	2	18
Quite difficult	1	9

Comments included:

"Had to look a few times."

"This information was really helpful."

"Didn't know where to find that information. Wasn't that clear. Rehabilitation as main section would help."

Can you find information about how professionals will work out what support you need after assessment?

All respondents found this information.

How easy was it to find the information?	Number of respondents	Percentage of respondents (%)
Very easy	9	82
Quite easy	2	18

Comments included:

"I had to look a few times."

"I already had assessment done so I didn't need this information but would be really helpful for others." "Really helpful information in here. Will share this with my GP as don't think they are aware of the guideline or the app for patients."

Can you find where you would record progress with your wellbeing in the symptom diary?

10 out of 11 users could find this information and found the information easy to find.

Comments included:

"No difficulties but really helpful to be able to record stuff here because you forget."

"No difficulties but really useful to have this."

I thought having the option to store your information here was helpful. Time with GP is short so you can't always say everything and I forget. Sharing this via the symptom diary is ideal."

"Every day is so different so it's useful being able to log how you are feeling. Useful to have it recorded in one place so it can be shared."

"Useful to record in here and share with GP and others. If I had this at start it would have helped me understand long COVID and manage it better. I wasn't told much at my GP."

"This is really helpful so I can discuss with GP. I can look back at it too."

How easy was it to enter symptoms into the diary?

All users who provided feedback found it very easy to enter symptoms into the symptom diary.

Functionality

Feedback from users indicates the app was easy to use and the instructions were clear. However, some users had difficulties with some functions such as navigation to the symptom diary.

Did you experience any problems with the app/website features and functions eg search, navigation menus, buttons, hyperlinks, entering text into the symptom diary?

2 out of 11 users who provided feedback experienced problems with the app's functions.

Comments included:

"It wasn't easy to go back. Kept having to go back to homepage."

"When you click on 'What can help' tab and click symptom diary, it takes you to information about the diary and gives the links to the app. Would be more useful if clicking from here took you straight to diary."

"Found it useful to add other symptoms that were not on list."

Other comments from Tactuum and Long Covid Scotland included:

"Want to be able to add daily comments and to be able to enter scores and comments retrospectively."

"I downloaded it a while ago but haven't used it since May. I remember getting frustrated at the amount of taps to get to symptom diary (3 before you actually log each symptom). I think I eventually I gave up because I found it overlapped with the app used for the pacing."

Ease of use

How easy was it to find the information?	Number of respondents	Percentage of respondents (%)
Very easy to learn how to use the app	10	91
Very difficult to learn how to use the app	1	9

Comments included:

"Most folk can navigate apps. So many apps these days that folk are used to them."

"Straightforward."

"Really clear which is what you need s can't concentrate for long times trying to find stuff."

Are explanations about how to use the symptom diary clear?

All users who provided found the explanation about how to use the app clear. Comments included:

"Even without instructions it's obvious what to do. Really easy to use."

"Simple instructions are useful."

"Clear instructions which is useful for people with long COVID due to brain fog."

"Really clear instructions."

"Been using the symptom diary once a week. I haven't shared with my GP yet but looking forward to doing so to help our conversation."

Navigation

Is moving between screens logical and appropriate?	Number of respondents	Percentage of respondents (%)
Always	10	91
Mostly	1	9

Design and visual appeal

How effective is the visual design of the app?	Number of respondents	Percentage of respondents (%)
Very effective	10	91
Fairly effective	1	9

A comment in relation to design included:

"Really liked the colours and icons in the app."

Overall impression

All users that provided feedback found the app and symptom diary very useful. Comments included:

"Something that if needed, people can use it to learn about long COVID so they can discuss with GP."

"It makes things easier being able to keep track on phone. Phones used for everything."

"It was this part of the app [symptom diary] that I found most helpful."

"Really useful. The app has everything people need to understand and live with long COVID."

"Really useful and hope it is used by people. Do GPs know this is available? My GP wasn't aware."

"Having health information in apps is helpful. Quick and handy. Can read anywhere and having the symptom diary in app is great to help stay in control."

Other comments via Tactuum and email included:

"I am very thankful for this app and it is great you're able to send the track of your symptoms directly to a medical professional. However, I do feel like the logging of symptoms is quite tedious and it would be easier if you could just click the number of the scale for each symptom"

instead of having to add 'new' for each symptom. It would be good to track my symptoms each day but it sometimes seems like a lot of effort. If there is anything that could be done I think you'd find more people logging symptoms more often."

"Just to let you know because of the app I sent it to a very dear friend in the south of England who had been suffering for a while and didn't know what was wrong. After getting the app she went to her doctor who has diagnosed long COVID and they are working with her to help her to try and recover. She is delighted to finally know what is wrong. A success for the app. A big thank you."

Quantity of information

All users who provided feedback said the amount of information in the app was suitable. Comments on the amount of information included:

"Might be too much for some people but having it in an app on phone is really helpful. People can go in and get what they need at any time and again and again for information if forgotten. Brain fog is terrible so people need something to go refer back to and read again."

"Good to have all the information so you can read in sections. Don't need to read all at once and can go back."

Would you recommend this app/website to people who may benefit from it?

All respondents would recommend the app to everyone living with long COVID.

What benefits does the app/website add compared to the PDF version of the booklet on long COVID?

6 out of 11 respondents said there is value in having both the app and PDF version for different audiences. 4 out of 11 respondents said the app makes the information more accessible to people and helps them to be involved in managing their condition. Comments included:

"PDFs are not so good to look at on a phone. The app is great, you're not going to lose app on phone but could lose a booklet."

"PDF may be useful for some people but most things are on phones now. We are all used to viewing information on our phones."

Views on likely impact of the app

Users were asked to score 0-10 on the likely impact of the app.

This app/website is likely to increase people's knowledge and understanding of how the long-term effects of COVID-19 will be managed

5 out of 11 people rated the score as 10. 2 people rated the score as 9, 2 rated it as 8 and 2 rated it as 7.

This app is likely to help inform discussions between people and their healthcare professionals

5 out of 11 people rated the score as 10. 5 people rated the score as 9 and 1 person rated the score as 8.

Comments included:

"Really useful app and hopefully it will help others manage their long COVID symptoms. I found it really helpful. I would write down symptoms but would use this instead."

"Excellent."

"Really helpful app which I hope gets used by people so they are more involved in management of their long COVID symptoms."

"Excellent to see HIS moving to this sort of thing."

"Useful to help people take responsibility for own health."

Conclusion

Usage

Data collected demonstrated good engagement with SIGN's first Patient Decision Support toolkit. Between January 2022 and November 2022, approximately 2,000 users were engaged with the toolkit. These numbers suggest a lower level of activity on the app compared with the web version. Use of the toolkit peaked in May 2022 which was the time the toolkit was being promoted in the media.

User feedback

Feedback suggested that the app is useful for people with long COVID, particularly the symptom diary to allow people to monitor their symptoms and share with their GP. Feedback suggested the app is easy to use but there is potential to improve navigation and ease of entering symptoms. Comments suggested that people are familiar with using apps and more likely to view information on phones.

Recommendation about updating the toolkit

The SIGN Patient Decision Support toolkit for 'Managing the long-term effects of COVID-19' was welcomed and it would be beneficial to users to update this when there are updates to the guideline.

Recommendations about whether or not further SIGN digital toolkits for patients and the public should be considered in the near future

There are possible explanations for lower download numbers from the App store and Play store compared with the web version, including lack of awareness of the app. Engagement numbers with the app suggests this format is acceptable and suitable for users of health information from guidelines.

A small number of users provided feedback, but the feedback suggests that digital toolkits for sharing information from guidelines with users should be considered for the near future.

The need for a toolkit for patients and the public should be identified through discussion with the guideline development group and engagement with intended users through third sector groups and other networks. It will be necessary to check that a digital tool does not already exist, to avoid duplication. Planning should take place to identify the resources and skills required for this work. Promotion of digital toolkits with the intended audience must take place to ensure use.

Acknowledgements

We would like to acknowledge the support provided to develop this app by Ann Wales, Decision Support Programme Lead, the Digital Health & Care Innovation Centre, the NHS Greater Glasgow and Clyde Knowledge Services team and Tactuum.

We would also like to thank the people with lived experience of long COVID who advised on the design and content of this app.

Appendix: Questionnaire

About you

1. Please tell us about who you are:

- ☐ I am a representative/employee of a voluntary organisation supporting people with long COVID
- ☐ I have direct experience of long COVID (as either a service user/patient/carer of a person with long COVID)
- ☐ Other

2. Please tell us which version you are using:

- ☐ App
- ☐ Website

Findability of information

3. Did you find information on what will happen at an assessment successfully?

- ☐ Yes
- ☐ No

4. How easy was it to find?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

5. Please highlight any difficulties you had.

6. Can you find information on things people can do to help themselves?

- ☐ Yes
- ☐ No

7. How easy was it to find?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

8. Please highlight any difficulties you had.

9. Can you find information on what will be discussed with you when developing and agreeing your rehabilitation and management plan?

- ☐ Yes
- ☐ No

10. How easy was it to find?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

11. Please highlight any difficulties you had.

12. Can you find information about how professionals will work out what support you need after assessment?

- ☐ Yes
- ☐ No

13. How easy was it to find?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

14. Please highlight any difficulties you had.

15. Can you find where you would record progress with your wellbeing in the symptom diary?

- ☐ Yes
- ☐ No

16. How easy was it to find?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

17. Please highlight any difficulties you had.

18. How easy was it to enter symptoms in the diary?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

User Experience

Functionality

19. Did you experience any problems with the app/website features and functions – eg search, navigation menus, buttons, hyperlinks, entering text to the symptom diary?

- ☐ Yes
- ☐ No

20. If yes, please provide details

Ease of use

21. How easy is it to learn how to use the app/website?

- ☐ Very Easy
- ☐ Quite Easy
- ☐ Quite Difficult
- ☐ Very Difficult

22. Please provide details of any problems you had with ease of use.

23. Are explanations about how to use the symptom diary clear?

- ☐ Yes
- ☐ No

24. Please provide more details.

Navigation

25. Is moving between screens logical and appropriate?

- ☐ Always
- ☐ Mostly
- ☐ Rarely
- ☐ Never

26. Please provide details of any problems you experienced with the navigation

Design – size, colours, visual appeal

27. How effective is the visual design of the app/website?

- ☐ Very Effective
- ☐ Fairly Effective
- ☐ Not Very Effective
- ☐ Ineffective

28. Please highlight any issues you identified with the visual design.

Usefulness and impact

Overall impression

29. What is your overall impression of the app/website?

- ☐ Very Useful
- ☐ Fairly Useful
- ☐ Not Useful

30. What is your overall impression of the symptom diary?

- ☐ Very Useful
- ☐ Fairly Useful
- ☐ Not Useful

31. Please provide more detail.

Quantity/amount of information

32. Is the amount of information provided in the app/website suitable?

- ☐ Yes
- ☐ No

33. Please provide more detail.

34. Would you recommend this app/website to people who may benefit from it?

- ☐ I would not recommend this to anyone
- ☐ I may recommend this to some people who are affected by long COVID
- ☐ I would recommend this to everyone who is affected by long COVID

35. What benefits does this app/website add compared to the PDF version of the booklet on long COVID?

- ☐ The app has no benefits
- ☐ There is value in having both the app/website and the PDF for different audiences
- ☐ The app/website makes the information more accessible to people and helps them be involved in managing their condition
- ☐ Other (please tell us)

36. If 'Other', please tell us why.

Do you agree with the following?

37. This app/website is likely to increase people's knowledge and understanding of how the long-term effects of COVID-19 will be managed.

- ☐ Strongly Agree
- ☐ Slightly Agree
- ☐ Neither Agree or Disagree
- ☐ Slightly Disagree
- ☐ Strongly Disagree

38. This app is likely to help inform discussions between people and their healthcare professionals

- ☐ Strongly Agree
- ☐ Slightly Agree
- ☐ Neither Agree or Disagree
- ☐ Slightly Disagree
- ☐ Strongly Disagree

39. Any other comments

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