Involving patients and the public in guideline dissemination and implementation

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Key messages of this chapter

- Patient and public involvement in dissemination strategies is valuable for developing educational materials, online resources and implementation tools that public and professional audiences find useful, understandable and convincing.

- A combination of strategies for involving patients and the public is essential when disseminating guideline recommendations to patients and the public. This includes media releases, digital tools, distributing patient versions of guidelines, and appointing community champions.

- Patient organisations and charities can promote the guideline (and its patient version) to patients and the public through various routes. These include social media, their newsletter, at conferences, by hosting it on their website, and including it in the information packages provided to their members.

- Providing patients and the public with information about conditions or procedures recommended in guidelines can help them to understand the care and treatment choices available to them based on the evidence. It can also support shared decision making about their own health. This can help with implementing guideline recommendations.

- Patient organisations and charities can promote guideline recommendations to professionals through educational materials, educational meetings such as conferences, and mass media information.

- Attitudes of healthcare professionals and lack of agreement with recommendations can act as barriers to implementation. Patients, the public, and patient organisations can play a key role in addressing these problems by becoming involved with implementation strategies.
Top tips

- Patients and the public may have conflicting views about recommendations, and these need to be understood and resolved during the guideline development process.
- Think about how patients and the public can be involved in dissemination and implementation plans during the development of guidelines and not at the end of the process.
- Focus on developing implementation strategies in which patients and the public can play an active role.
- Provide patients and the public with access to guideline recommendations and their rationales by using patient versions of guidelines and other decision-making tools to promote awareness of them and encourage their use in people’s own care.
- Encourage and support patients to become involved in developing dissemination and implementation strategies for self-management recommendations.
- Raise awareness of tools with patients and the public to promote decision making about care and treatment, thereby helping with implementation of guideline recommendations.
- Patient and public members of guideline groups who become involved with dissemination and implementation strategies should be trained and supported.
- Provide a named contact for patients, the public, and organisations to contact.
Aims of this chapter

This chapter focuses on ways in which recommendations from guidelines can be promoted to maximise impact on patient care. It describes ways that patients, the public and organisations can be involved in guideline dissemination and implementation strategies. It aims to describe who to involve in this process and how they can be involved in planning and delivery of dissemination and implementation strategies. It does not give guidance or advice on how to implement guidelines.

The chapter highlights a wealth of examples from guideline developers and other organisations on involving patients and the public in the dissemination and implementation of guidelines.

Dissemination of guidelines

Dissemination of guidelines is about raising awareness among the public, patients and professionals of the existence and content of the guideline. Dissemination plans are ideally developed in parallel with developing recommendations (SIGN 2019). Dissemination plans are needed to clarify at the start of the guideline development process the target audience, which will determine the scope, objectives, format, style and wording of the recommendations as well as the tools for dissemination (NICE 2020, Schipper et al. 2016, Armstrong et al. 2018).

Patient and public involvement in dissemination strategies is valuable to develop educational materials, online resources and implementation tools that public and professional audiences find useful, understandable and convincing. This is demonstrated in case studies 1 and 2.

Case study 1

On publication of their epidermolysis bullosa (EB) psychosocial guideline in 2019, DEBRA International circulated the news to:

- 45 member patient support groups
- 3,422 social media followers
• 400 members of the DEBRA International Research Involvement Network
• 530 members of the international EB clinical network (EB-CLINET), and
• 407 members of the clinical practice guideline network.

DEBRA International also gave presentations on the guideline at the annual congress in Switzerland (2018) and the first EB World Congress ‘EB 2020’ (2020), attended by 690 delegates representing 215 organisations from 54 countries.

Patient support groups involved with DEBRA International are patient-founded and led (many people within the clinical practice guideline network are also affiliated with these groups). They further supported dissemination in the following ways:

• recirculating news about the guideline to their members and signposting to the document hosted on the DEBRA International website
• hosting the guideline on their own websites
• presenting the guideline at events, such as national patient and clinical meetings, study days, and forums
• presenting real-life patient stories to complement the guideline content
• liaising with organisers of other groups to promote it, for example, following discussions with DEBRA Norway, it was included in the programme of the European Rare Disease Day (2019).

At EB 2020, DEBRA International launched 3 patient versions of the guideline to support adults with EB, parents of children with EB, and both caregivers and patients in understanding the multidisciplinary team involved in their care processes. These are hosted on the DEBRA International website, circulated by the same means, and freely available. Currently, DEBRA Belgium is translating these into Dutch, and there have been requests for Turkish versions.

DEBRA International started a programme to develop EB infographics for low-resource countries to help EB patients, their families, and doctors in
countries without a DEBRA group. EB infographics are more pictorial ensuring key guideline recommendations remain consistent no matter where people live. For the EB Psychosocial guideline, the ‘Healthy mind and control’ EB infographics are currently being developed.

Case study 2

The Scottish Intercollegiate Guidelines Network (SIGN) produced the first UK guideline on children and young people exposed prenatally to alcohol. The guideline is also accompanied by downloadable information for individuals having assessment for fetal alcohol spectrum disorder (FASD) and information for clinicians to support individuals and their carers before, during and after the assessment process. To raise awareness of the guideline, there was extensive coverage on social media with retweets from various charities including NOFASD-UK, Scottish Drugs Forum, Alcohol Awareness, FASD Network UK, and Adoption UK. This was to endorse the impact of the SIGN guideline on patients and carers in Scotland. SIGN involved a young person living with FASD in the production of a YouTube video animation on FASD that used their story to increase awareness of the condition and the guideline recommendations with both professionals and the public. This was a different approach, which suited audiences with different learning styles and allowed access to new audiences on a wider platform. The video received 930 views within the first 6 months of publication and supported social media promotion of the guideline recommendations.

Strategies for disseminating guidelines to patients and the public

To ensure patients and the public are aware of guideline recommendations, a combination of strategies is essential (Schipper et al. 2016). One strategy is to disseminate guideline recommendations and their rationales using patient and public versions of guidelines in various formats and other decision-making tools (DECIDE
Involving patients and the public, Schaefer et al. 2015, Santesso et al. 2016, Utrakar et al. 2018). Details on the development of these and how patients and the public are involved in the process is provided in the chapter on how to develop information from guidelines for patients and the public.

When disseminating guideline recommendations through patient and public versions of guidelines, the involvement of patients and the public in multiple dissemination strategies outlined below have been found to be effective (Schipper et al 2016). These include:

- media releases involving patients and the public
- digital tools, such as websites and apps
- providing copies of the patient and public version to public places such as libraries
- using community champions to disseminate patient versions of guidelines to patients.

**Media releases**

Involving individual patients, the public, and carers in media releases provides a useful platform to highlight their personal stories and can help to raise awareness of guideline recommendations. Patients, carers and members of the public, who have helped develop guidelines, should be supported to be involved in media releases to highlight the importance of making diagnosis and treatment decisions based on the latest evidence. Patients and the public can also help promote awareness that patients helped develop the guideline to ensure that the needs of users shaped the recommendations. Consent should be collected from the patient, carer or member of the public to share personal experiences of care in media releases. The individual’s contact details should not be shared, and comments should be sent to the guideline organisation. Any criticism should be responded to directly by the guideline organisation. Media releases shared via social media should be shared from the guideline organisation’s social media account.

**Digital tools**

The use of digital tools, such as apps and websites, can help to raise awareness of guideline recommendations. Web-based self-management programmes can serve
as a tool for healthcare professionals to share evidence-based information to help patients to successfully manage their conditions (Brosseau et al. 2012).

**Community champions**

People living with particular conditions have expert knowledge to become community champions, and it is both feasible and effective to involve them in adaptation of information from guidelines for patients, for example self-management guides (Campbell et al. 2018). Patient, public, and carer members of guideline development groups can act as champions for change. Together with other patient champions, they are in a good position to communicate to others the importance of the evidence when making decisions about their own care.

Providing support and training for patients and members of the public to become community champions is one approach that guideline developers can take to disseminate patient versions of guidelines to patients and the public. This is highlighted in SIGN 50’s guideline developers handbook. Community champions educate and raise awareness of guidelines by organising stalls, talks and presentations at various places where patients and the public are likely to be. Examples include health conferences, community groups and local festivals. Patients and members of the public can also be supported to participate in virtual events, such as conferences and webinars, to raise awareness of guideline recommendations. **Case study 3** highlights how patient and public members of guideline groups can be trained and supported to become community champions to assist with dissemination of guidelines.

**Case study 3**

SIGN appointed patient members of guideline groups and members of the public to become Awareness Volunteers (Community Champions). In addition to patients who were members of guideline development groups, others were recruited through patient groups, charities, voluntary organisations and volunteer centres.

Expectations of the role were clarified. The role included contributing to advertising materials, exhibiting at events, conferences and community...
hospitals, and delivering talks to patient and community groups about SIGN and patient versions of guidelines. In addition to this, Awareness Volunteers delivered talks to student nurses to raise awareness of guidelines and patient versions of guidelines.

SIGN provided training and support, which included:

- training on guideline development processes
- practical tasks to develop communication and presentation skills
- a named contact for individuals, who could support them in their role
- availability of a buddy for people new to the role.

Resources at the organisational level needed to successfully involve patients and members of the public in dissemination groups included:

- staff time to recruit, train and supervise patient and public members (see the chapter on recruitment)
- sufficient finances to reimburse out-of-pocket expenses, including travel expenses, childcare expenses and carer allowance (see the chapter on recruitment)
- sufficient finances for publicity materials
- possibly, financial compensation for patient and public representatives’ time and work.

Patient organisations and networks of patients

Patient organisations and charities can promote the guideline (and its patient version) through social media, in their newsletter, at their annual conference, hosting it on their website (see case study 4), and including it in the information packages provided to their members.

The benefits of organisations and charities promoting guidelines include that:

- they have an established and engaged membership base
• patients and the public may be more likely to access information through their channels when searching for information
• they are a trusted source of information for the public, and
• their knowledge of the patient and public group can enable them to pick out and phrase the most relevant recommendations for their audience.

Patient organisations can organise events where people share their experiences and take part in training and education (Schipper et al. 2016). Recommendations from guidelines can be disseminated at these events organised for patients and the public, for example, through posters, pocket cards, handouts and summaries. Discussions can take place on how patients can use them to help them take part in shared decision making (see the chapter on how to develop information from guidelines for patients and the public). Patient organisations may also provide telephone advice based on guideline recommendations.

Networks or ‘virtual panels’ of patients and the public can aid the dissemination of recommendations from guidelines as shown in SIGN 100’s handbook for patient and carer representatives. SIGN’s Patient Network members are alerted when new guidelines or patient versions of guidelines are published. Network members can raise awareness of them by circulating them to patients and other patient organisations.

**Case study 4**

**Patient organisations promoting NICE guidelines:**

Mind provides links to NICE guidance in their treatment and support sections of topics. For example, in schizoaffective disorder.

The MND Association created patient friendly resources to support the NICE guideline on motor neurone disease (NG42 2016). These include a pocket guide containing a summary of what you should expect from your care and an animated video setting out key aspects of the guideline.
Strategies for disseminating guidelines to professionals

The involvement of patients and the public in dissemination plans can be crucial in increasing awareness of the guideline, not only among patients and the public, but also among healthcare professionals. Various strategies exist for disseminating guidelines to professionals, including educational materials, educational meetings such as conferences, and mass media information. Evidence shows that when multiple strategies for dissemination and implementation of guidelines are used, significant improvements in knowledge, practice and patient outcomes are likely (Fischer et al. 2016, Schipper et al. 2016).

Many patient organisations, charities and their networks include close connections with health and social care professionals in their disease area. They can thus promote the guideline to professionals through social media, on their websites, and at events and workshops that are attended by both professionals and patient organisations. Patient organisations and charities also send members to attend conferences aimed at (and organised by) healthcare professionals, to promote their own organisations and learn about new developments concerning their condition. Patient and public representatives from guideline groups can also be trained and supported by guideline organisations to speak at relevant conferences to raise awareness of the guideline with healthcare professionals. Case study 3 provides details of support and training for this role.

Patients and the public who have been involved with the development of guidelines can be supported to take part in media releases aimed at professionals to raise awareness of guideline recommendations (see case study 5).

Case study 5

SIGN published its guideline on risk reduction and management of delirium on World Delirium Awareness Day. To help raise awareness of the guideline, the patient representative from the guideline development group was involved in a media release. They were supported to share their experience of delirium and how the guideline could improve care in a blog and video.
Recruiting patients and members of the public as community champions can also help to raise awareness of guidelines with health and social care professionals (see case study 3).

**Implementation of guidelines**

Barriers to implementation of guidelines by healthcare professionals include lack of awareness and lack of familiarity with the guideline and its recommendations. Attitudes of healthcare professionals and lack of agreement with recommendations can also act as barriers to implementation (Fischer et al. 2016). Patients and patient organisations can play a key role in addressing this problem by becoming involved with implementation strategies (SIGN 2019). Structured implementation can improve adherence to guideline recommendations.

Implementation of guidelines includes developing additional tools, documents or campaigns to encourage awareness and use of the guidelines. These can be designed either for patients and the public, or for professionals. Patients and public members of guideline development groups can be involved in both the design, testing and promotion of such implementation strategies.

After implementation tools have been developed, patient and public members and organisations can help promote and distribute these tools. This is usually alongside the dissemination of the guideline itself, using dissemination strategies such as those described in this chapter.

Implementation tools can include web-based resources for health and social care professionals or patients to help implement the guideline recommendations, for example, podcasts and video presentations. They can also include the development of more- or less-extensive public awareness campaigns and strategies. Case studies 6, 7, 8, 9, 10 and 11 demonstrate the various strategies and tools that can support implementation of guideline recommendations.

**Case study 6**

As part of implementation of the SIGN glaucoma guideline a poster was created highlighting key recommendations for use with community
optometrists. A patient representative on the guideline group was involved with the design of these and dissemination.

Case study 7

Patient organisations can promote guidelines in their training for patients and professionals to encourage a change in practice. To help with implementing SIGN’s guideline on children and young people exposed prenatally to alcohol (SIGN156), Adoption UK Scotland highlights recommendations from the guideline in training they provide for professionals to help support families.

Information from guidelines for patients and the public

Information for patients and the public, such as patient versions of guidelines and plain language summaries, give patients, carers and members of the public access to recommendations in guidelines. This can help with implementation (see the chapter on how to develop information from guidelines for patients and the public). Patient information about conditions or procedures can help people to understand the care and treatment choices available to them based on the evidence and can support shared decision making about their own health (Bradley et al. 2019). Information from guidelines can help patients to evaluate their own care because they can monitor whether their own care is in line with options recommended in guidelines. It allows patients to discuss recommended treatment options with healthcare professionals and to find out why they are not being offered recommended treatments. Providing patients with this information can help to change the behaviour of the healthcare professionals caring for them. Case study 8 demonstrates this.
Case study 8

The National competence service for simultaneous substance misuse and mental illness in Norway has produced a wide range of resources for patients and professionals, which they publish on their website. These resources include a ‘recommendation card’ for patients that highlights the 10 most important recommendations so that patients and relatives have increased knowledge of what kind of assessment, treatment and follow-up to expect from their healthcare professionals.

Example

The Norwegian guideline for assessment, treatment and follow-up of people with substance abuse and mental illness was developed by the Norwegian National Directorate of Health, medical associations, the Knowledge center for dual diagnosis and 10 user organisations. A user version of the guideline was developed by the Knowledge center for dual diagnosis in collaboration with several user and relatives organisations. They have also developed and published several other resources:

- Video collection of examples on how assessment tools and motivational interviews can be used in clinical work, as well as videos with representatives from user organisations that address several important topics.
- Web page with an introduction to motivational interview (MI), with clinical examples of how the various MI techniques can be used, as well as videos that show how the method can be used in clinical work. Care givers and patients can order free cards on assessment of drug use and MIs.
- Dual-diagnosis TV consisting of continuous lectures, interviews and other short snippets.
- Contact information for the Expert Council, a group where the National knowledge center for dual diagnosis, user organisations, social entrepreneurs, and professional organisations share experiences and
discuss key topics within the drug or substance misuse and mental health field.

A web resource for users with:

- information about follow-up and treatment
- guideline and guidance documents from the authorities
- links to all user organisations, foundations, and social entrepreneurs in the area of substance abuse and mental health
- user rights
- digital self-help programmes or guidance
- helplines and humanitarian organisations to contact for practical help.

In addition to equipping patients with information about treatment options, raising awareness of guideline recommendations can promote their involvement in other areas, such as implementation of recommendations in relation to healthcare-associated infections. Raising patient's self-awareness on the risks and transmission of infections is one method to promote their involvement in infection prevention and control interventions. Involving patients as partners can promote conversations with professionals about infection control, for example, the patient can remind healthcare professionals to wash their hands (Fernandes Agrei et al. 2019).

**Self-management tools**

Self-management is an important component of care for patients with chronic conditions. Research shows that patients view guidelines as potential sources of self-management support (DECIDE patients and the public, Vernooij et al. 2016). It is therefore crucial that every effort is made to develop implementation strategies in which patients can play an active role. One example is online education tools that promote shared decision making. Brosseau et al. 2012 found that an online evidence-based educational programme delivered through Facebook could improve the knowledge, skills, and self-efficacy of patients with arthritis in relation to evidence-based self-management rehabilitation interventions. Facebook offers a way
for healthcare professionals to interact with their patients and share guideline recommendations to promote shared decision making.

Involvement of patients in innovative implementation strategies for self-management recommendations can increase their feeling of having control over their life. For example, self-monitoring, the use of short message services (SMS), diaries, reminders and action plans can serve as tools to support self-management for patients with conditions, such as cancer pain, asthma and diabetes. In patients with cancer pain, SMS alerts and interactive voice response (through a mobile phone) can be used to report and assess pain, allowing patients to be more involved with their pain management. In patients with asthma, action plans can encourage patients to be in more control of their asthma. The use of such tools may be a way to encourage patient empowerment because the patient’s role in managing their condition becomes more active, thus aiding the implementation of self-management recommendations (te Boveldt et al. 2012, Vernooij et al. 2016). Case study 9 provides an example of how patient organisations can support implementation of self-management recommendations.

Case study 9

A UK patient organisation, the National Rheumatoid Arthritis Society, developed a framework of supported self-management for people with newly diagnosed rheumatoid arthritis with the aim of improving patient outcomes. The Right Start service and resources supports the implementation of recommendations on self-management in the NICE guideline on rheumatoid arthritis in adults: management (NG100 2018) and related quality standard (QS33 2013). Right Start outcomes are being independently evaluated as part of a quality improvement programme and national audit.

Development of apps and web-based resources

Often apps and web-based resources are developed for health and social care professionals and patients to help with implementing guideline recommendations.
Examples of patients and public members being involved in developing such implementation materials are highlighted in case studies 10 and 11.

Case study 10

To help with implementation of the NICE guidelines, patients or service users were involved in developing podcasts.

NICE has worked with patient organisations, such as the British Lung Foundation, Prostate Cancer UK and the British Skin Foundation, to develop podcasts. Examples include:

- **Why you should get the flu jab** – with the British Lung Foundation
- **How is prostate cancer managed and treated?** - with Prostate Cancer UK
- **What is melanoma and how can I prevent it?** – with the British Skin Foundation and a patient.

Individual patients or service users were also involved in developing the following podcasts:

- **Care of women and their babies during labour and birth**
- **Which contraceptive method is best for me?**

Case study 11

To help with implementing the guideline developed by SIGN, NICE and Royal College of GPs on managing the long-term effects of COVID-19 (2020), an app is in development for patients and the public. A patient who was involved in developing the guideline was involved with this at both the planning stage and early user testing stage of the app development. Interactive content is being developed to support self-management. Further user testing with patients and the public is planned.
Public awareness-raising campaigns

Patient organisations and charities can be involved in using a guideline to develop education programmes for patients or people at high risk of a condition. Informing patients and the public about a condition and how best to prevent, diagnose and treat it can support the implementation of a guideline by encouraging patients to seek care in accordance with the guideline. It also ensures that professionals treat conditions in patients in accordance with the new, updated or existing guidelines. In addition to being organised or co-developed by patient organisations or charities, patients can be involved in delivering such education programmes.

Individual patients and members of the public can be involved in raising awareness of public health messages, based on evidence. Case study 12 provides an example of this.

Case study 12

World Antibiotic Awareness Week (WAAW) is a global campaign held each year in mid-November. The Scottish Antimicrobial Prescribing Group (SAGP) and Health Scotland lead activities in Scotland to support WAAW and work closely with colleagues in Public Health England and professional groups to coordinate activities and share feedback. The aim is to raise awareness among health and social care staff, patients and the public about the need to use antibiotics more wisely to stop antimicrobial resistance. Since 2019, the campaign slogan has been ‘Keep Antibiotics Working’ and SAPG has promoted key messages using social media, the SAPG website, and radio adverts. Health Scotland has supported the campaign using posters in community pharmacies, GP practices and other community settings. Antimicrobial Management Teams in Scotland lead their Health Board campaign and local activities are supported by SAPG communications and resources. Public partners (volunteers) play an important role in these local activities through promoting the key messages and engaging healthcare staff and members of the public in discussions about the campaign.
Evaluating service provision and commissioning

Patient organisations and charities can evaluate the quality and provision of services using guidelines as a measure. They can develop research projects and frame questions about the availability and quality of provision to evaluate if services and experiences are aligned with published guidance.

Patient organisations and charities can then use guidelines to develop or scrutinise service improvement plans, to ensure they align with the evidence of what is effective and good value care. Case studies 13 and 14 provide examples.

Case study 13

Healthwatch Bucks in England wanted to find out about the experiences of people treated in the hospital emergency department after a self-harm injury. They wanted to see if the NICE clinical guideline on self-harm in over 8s (CG16 2004) was being followed. They worked with a mental health charity, Buckinghamshire MIND, who carried out interviews with service users. As a result of the project, Healthwatch Bucks made recommendations aimed at supporting implementation of the NICE guideline. Local health service organisations responded by producing a joint action plan that implemented several recommendations, including those around privacy and consent.

Case study 14

Pancreatic Cancer UK worked with University Hospital Birmingham to develop a project to deliver fast track pancreatic cancer surgery.

The patient organisation worked in partnership with the hospital to implement NICE guideline recommendations to improve access to services and reduce waiting times. The project enabled patients to have surgery in 16 days rather than 65 days, increased the number of those having surgery
by more than a fifth, and achieved a cost–saving benefit of £3,200 per patient.
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