CICER
Tacaíocht don Treoirlíne Chliniciúil
Clinical Guideline Support

FINAL REPORT

Scalable Training And Knowledge Exchange on guideline development for patients, public, and health professionals: The STAKEholder project

March 2026

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

NATIONAL CLINICAL EFFECTIVENESS COMMITTEE

HRB
An Bord Taighde Sláinte
Health Research Board

About CICER

In 2016, the Department of Health requested that the Health Research Board (HRB) fund an evidence synthesis service to support the activities of the Ministerially appointed National Clinical Effectiveness Committee (NCEC). Following a competitive process, HIQA was awarded research funding spanning the period from 2017 to 2024 to produce the evidence to support the development of National Clinical Guidelines. This funding was renewed through a competitive process to support the work of the Centre in Ireland for Clinical guideline support and Evidence Reviews (CICER) from 2024 to 2028. The CICER team comprises a dedicated multidisciplinary research team supported by staff from the Health Technology Assessment team in HIQA, the Discipline of Public Health and Primary Care in the School of Medicine in Trinity College Dublin, as well as national and international clinical and methodological experts.

With regard to clinical guidelines, the role of the CICER team is to independently review evidence and provide scientific support for the development (by guideline development groups (GDGs)) of National Clinical Guidelines for the NCEC. The CICER team undertakes systematic reviews of the clinical effectiveness and cost-effectiveness of interventions included in the guidelines, as well as estimating the budget impact of implementing the guidelines. The CICER team also works closely with the GDGs and provides tailored training sessions; assists in the development of clinical questions and search strategies; performs systematic reviews of international clinical guidelines and supports the assessment of their suitability for adaption to Ireland; and supports the development of evidence-based recommendations informed within the National Clinical Guidelines.

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Plain Language Summary

Training on Clinical Guideline Development for Patients, Public, and Health Professionals: The STAKEholder Project

Key messages

- Clinical guidelines work best when they are created together with patients and health professionals.
- We wanted to support patients and health professionals to be more involved in creating clinical guidelines.
- In partnership with patients and health professionals, we made online learning materials that help to explain how clinical guidelines are created and prepare patients and health professionals to get meaningfully involved.
- We held a conference to bring patients and health professionals together with those who create guidelines and health technology assessments to exchange knowledge and ideas.
- We believe the project is a helpful step towards improving the involvement of patients and health professionals in creating clinical guidelines.

Background

A clinical guideline is a set of recommendations for a certain illness or situation, published by a trusted organisation. The goal of a clinical guideline is to help doctors, nurses, other health professionals, and their patients to make the best possible decisions about their care. A clinical guideline is created through a careful process. There are a lot of steps involved in creating a clinical guideline and the process can take up to two or three years.

Each clinical guideline is developed by a group called a guideline development group (GDG). The GDG is made up of people from different backgrounds. It is important that patients and health professionals are involved in creating the guideline, as they can help make sure that the guideline focuses on the right issues and is practical to use in the real world. Sometimes, patients and health professionals are not meaningfully involved in creating a clinical guideline.

This might be because they are not aware of the opportunity to get involved or because they do not feel prepared or confident to get involved.

What did we want to do?

In this project, we wanted to ensure that patients and health professionals had the information, confidence, and skills to get involved in creating clinical guidelines.

What did we do?

We brought together a group of patients, a group of health professionals, and an advisory group to help us design five products:

- a 40- to 60-minute online learning course about clinical guidelines for patients and the public
- a 40- to 60-minute online learning course about clinical guidelines for health professionals
- a two-minute video about clinical guidelines for patients and the public
- a two-minute video about clinical guidelines for health professionals
- a conference for patients, the public, health professionals, and developers of guidelines and health technology assessments.

We created these products based on advice and input from the groups.

What was the outcome?

We completed the first four products listed above and are sharing them more widely with patients, the public, and health professionals. For the conference, two hundred people attended the hybrid conference event and we got positive feedback from attendees. We hope that this project will result in more meaningful involvement of patients and health professionals in creating clinical guidelines in the future.

Table of Contents

About CICER **2**

Acknowledgements **3**

Plain Language Summary **4**

List of figures **7**

List of tables **8**

List of abbreviations **9**

1 Introduction **10**

2 Deliverables and Governance **13**

2.1 Deliverables 13

2.2 Establishment of the Advisory Group 13

2.3 Establishment of panels 14

3 Online Learning Materials **17**

3.1 Content outline development 17

3.2 Storyboarding phase 18

3.3 Building and testing 19

3.4 Deployment and dissemination 20

4 Conference **22**

4.1 Development of programme, preparation, and advertisement 22

4.2 Attendance 25

4.3 Content summary 26

4.4 Conference outcomes 32

5 Reflections and Outcomes **35**

5.1 Lessons learned 35

5.2 Outputs of the project 36

5.3 Impacts of the project 36

References **38**

List of figures

Figure 1: Project deliverables 13
Figure 2: Recruitment flyer for patient and public panel 15
Figure 3: Example of a draft storyboard 19
Figure 4: Flyer for conference..24
Figure 5: Participant satisfaction with knowledge exchange conference 33
Figure 6: Irish Pharmacy Union Review conference report 34

List of tables

Table 1: Advisory group members 14

List of abbreviations

CICER	Centre in Ireland for Clinical guideline support and Evidence Reviews
CEU	Clinical Effectiveness Unit
GDG	guideline development group
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
IPPOSI	Irish Platform for Patient Organisations, Science and Industry
NCEC	National Clinical Effectiveness Committee
PPI	patient and public involvement
RCSI	Royal College of Surgeons Ireland

1 Introduction

Clinical guidelines are sets of recommendations for a particular disease area or healthcare need, published by a trusted organisation, which aim to optimise patient outcomes.(1-3) Health professionals and policy-makers use clinical guidelines to help them deliver healthcare based on the best available scientific research.(3, 4) In Ireland, National Clinical Effectiveness Committee (NCEC) National Clinical Guidelines are created through a detailed process by guideline development groups (GDGs).(3)

There is a growing interest in engaging a range of stakeholders in clinical guideline development, namely patients, carers, the public, health professionals, administrators, payers, providers, and purchasers.(5) Engaging stakeholders in clinical guideline development has been recommended by international organisations, such as Guidelines International Network, National Academy of Medicine, and the National Institute for Health and Care.(2, 6, 7) In Ireland, the NCEC recommends considering the following stakeholder groups when developing National Clinical Guidelines:

- patients, carers, the public and their representative groups (considering for example, under-represented groups such as Traveller, migrant, and sexual and gender minority communities)
- health professionals (for example, doctors, nurses, allied health professionals, community health workers, social workers)
- healthcare managers (for example, healthcare administrators, programme managers)
- voluntary organisations and charities (for example, community representatives)
- education providers (for example, clinical educators, universities, academics)
- government (for example, government agencies, Health Service Executive (HSE), Department of Health)
- professional regulators and health services regulators
- international organisations that may be in the process or have completed relevant clinical guidelines
- others as appropriate(3) (for example, private healthcare providers, insurance companies, journal editors, legal or ethics experts).

Research has shown that effectively engaging with stakeholders helps to improve the implementability of clinical guidelines.(8) A number of tools have been developed to assist with involving groups in the clinical guideline development process, particularly patients and the public,(9, 10) highlighting the move internationally towards greater involvement of these groups in the clinical guideline development process. An example is the Guideline International Network Public Toolkit (https://g-i-n.net/toolkit), first published in 2012 and now a "living resource" with updates and additions being made "as experience, literature and methodology continue to evolve".

Amid the growing interest, there is still a gap in awareness among patients, the public, and health professionals regarding what clinical guidelines are, how they are created, and how to get involved in the development process.(11-13) This gap could potentially lead to a lost opportunity to ensure recommendations are based on real clinical practice and lived experience, and address outcomes that matter most to patients and families. While there are general frameworks for clinical guideline development, there is limited information on how and when to engage stakeholders throughout the clinical guideline development process.(14)

In light of this gap, the Centre in Ireland for Clinical guideline support and Evidence Reviews (CICER) was awarded a Knowledge Translation Award in 2024 by the HRB for "Scalable Training And Knowledge Exchange on guideline development for patients, public, and health professionals: The STAKEholder project". This project aims to improve knowledge exchange within the CICER programme by co-producing learning materials with patients and the public, and with health professionals. Co-production refers to the "active involvement of citizens in service planning, design and delivery including the direct involvement of users in the production, at least in part, of their own services".(15) Through the development and dissemination of learning materials, the project is intended to foster improved engagement of these stakeholder groups in the development of National Clinical Guidelines.

The STAKEholder project had the following objectives:

- to improve awareness and transparency around what National Clinical Guidelines are and how they are developed in Ireland

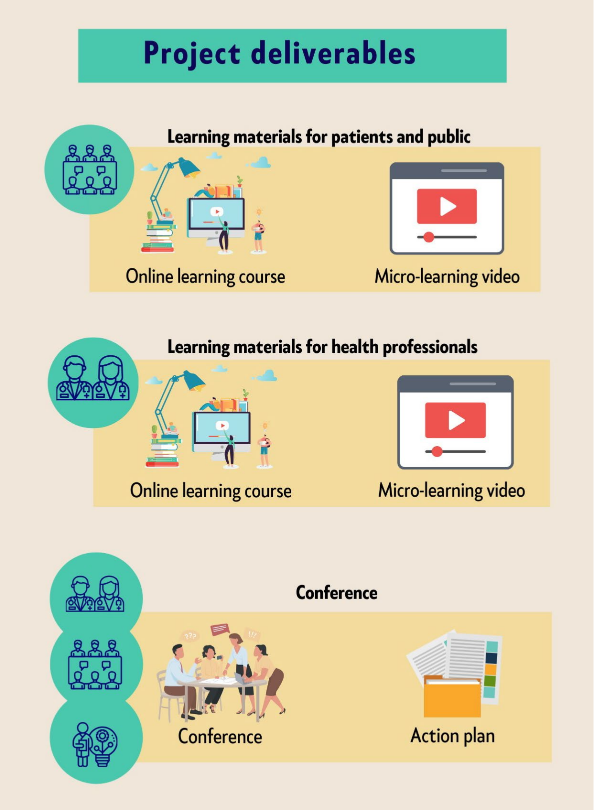
- to prepare patients, the public, and health professionals to be active National Clinical Guideline development group members
- to better understand patients’ and health professionals’ perspectives and preferences on how National Clinical Guidelines are created and implemented.

2 Deliverables and Governance

2.1 Deliverables

Within the Irish context, there is a lack of existing online learning materials designed specifically for patients and the public, and for health professionals who were new to National Clinical Guideline development. The project aimed to create innovative learning opportunities for patients, the public, and health professionals on the topic of clinical guideline development in Ireland. This involved the development and dissemination of micro-learning videos, online learning courses, and an in-person knowledge exchange conference, as shown in Figure 1.

Figure 1: Project deliverables



2.2 Establishment of the Advisory Group

The advisory group provided oversight to, and advised on all aspects of, the project. The group was composed of co-applicants and collaborators listed in the project grant application, plus additional members whose expertise was required as the project developed. Its members represented different stakeholder groups, such as patients and the public, health professionals, and subject matter experts. The members of the advisory group and their role is outlined in Table 1. The advisory group met in March and September 2025.

Table 1: Advisory group members

Name and organisation	Area of expertise
Prof. Byron Powell, Washington University	Implementation science
Caoimhe O'Connell, Health Information and Quality Authority	Communications
Dr. Celine Larkin, Health Information and Quality Authority	Clinical guideline development, implementation science
Dr. Colm Henry, Health Service Executive	Health system leadership, decision maker
Dr. Kieran Walsh, Health Information and Quality Authority	Evidence synthesis, clinical guideline development
Dr. Louise Larkin, Health Information and Quality Authority	Patient and public involvement, project management support
Dr. Mairin Ryan, Health Information and Quality Authority	Evidence synthesis, clinical guideline development
Dr. Melissa Sharp, Health Research Board	Communications
Michelle O'Neill, Health Information and Quality Authority	Evidence synthesis, clinical guideline development
Dr. Paul Kavanagh, Health Service Executive	Public health medicine, evidence synthesis
Stacey Grealis	Patient and public involvement
Prof. Susan Smith, Trinity College Dublin	General practice, evidence synthesis

2.3 Establishment of panels

Two panels were formed to support this work and represent the interests and perspectives of the learners, namely

(a) patients and the public
(b) health professionals.

The panels played an integral role in shaping the development of the content and format of the key deliverables of the project, namely the online learning courses, micro-learning videos, and conference. The panel members were recruited in consultation with advisory group members with expertise in involving patients and health professionals in research. Members with a range of experience (from none to very experienced) in National Clinical Guideline development were sought for recruitment.

2.3.1 Patient and Public panel

All stages of the Patient and Public panel recruitment were co-led by our patient partner co-investigator, Stacey Grealis. An advertisement poster was co-designed with the HIQA

Communications and Stakeholder Engagement team and patient partner co-investigator, to recruit members to the Patient and Public panel (Figure 2). This was circulated to patient and public organisations and representatives, through the PPI Ignite Noticeboard, and through The Irish Platform for Patient Organisations, Science and Industry (IPPOSI). The call was advertised in April 2025 and remained open for two weeks.

The application process began with an application form, which comprised of open-ended questions around applicants' understanding of clinical guidelines, their experience, and their motivation for applying. There was a total of 30 applications. After staff and patient partner co-investigators reviewed the applications, applicants were shortlisted for a 20-minute call over Microsoft Teams. On the call, applicants had the opportunity to discuss the role and ask any questions they might have about the project. Ultimately, six members were selected for the patient and public panel. There was diversity in the panel in terms of age (ranging from 35 to 64 years), experience of guidelines (no experience to experienced), gender (two men, four women), and geographical distribution (two from Munster, two from Leinster, and two from Connacht). The patient and public panel met a total of three times online between May 2025 and August 2025, with a typical meeting duration of two hours.

Figure 2: Recruitment flyer for patient and public panel

CICER JOIN OUR PANEL

Do you want to help shape clinical guidelines in Ireland?

- The **Centre in Ireland for Clinical guideline support and Evidence Reviews (CICER)** in Health Information and Quality Authority (HIQA) is building online learning resources. These resources will help patients and the public to understand how clinical guidelines are developed.
- We need your help to build these learning resources to make sure they are useful to learners.

WHO ARE WE LOOKING FOR?

- Curious about clinical guidelines
- People with or without experience in developing clinical guidelines
- Have some basic computer skills to join online meetings and review documents
- Anyone aged 18 years or older

WHAT WOULD BE INVOLVED?

- 2-3 online meetings lasting about 1.5 to 2 hours between May and October 2025
- Some follow up by email, phone or video calls
- Guiding the content, design, and structure of learning resources, along with ways to share the resources

APPLY BY 7th MAY, 2025

Fill the form to apply:
https://hiqa.qualtrics.com/jfe/form/SV_5hCXFSj12RBoJEy

For further information, please contact:
Shibu Shrestha
sshrestha@hiqa.ie
085-8556-495

2.3.2 Health Professional panel

For the recruitment of members for the health professional panel, we reached out to previous and current GDG members, national clinical programmes, and the Clinical Effectiveness Unit (CEU). The final panel of health professionals consisted of seven members: clinicians, allied health professionals, programme managers for National Clinical Guideline development groups, a clinical guideline methodologist, and a representative from the CEU. Their clinical areas included infectious disease, mental health, chronic disease, and cancer. Similar to the patients and the public panel, members had a range of experience in guideline development. This panel met once online in April 2025. Thereafter, health professionals provided input and feedback online.

3 Online Learning Materials

One set of key deliverables of the STAKEholder project was online learning courses. Two 40- to 60-minute online learning courses were developed; one for patients and the public and one for health professionals, with the aim of strengthening knowledge about National Clinical Guideline development in Ireland. Two micro-learning videos were also developed; these are approximately two minutes long and designed to spread general awareness about National Clinical Guideline development in Ireland and how stakeholders can participate in the process. In this section, we present the process for developing these materials and summarise related outputs and outcomes.

3.1 Content outline development

The project relied on co-production methodology to develop the learning materials. For this, initial meetings were organised with the Advisory group, health professionals panel, and the patients and the public panel. In these meetings, the project team presented the proposed project activities and some content ideas that could be included in the online learning course. The attendees shared topics that they thought should be included in the course. The health professional panel members suggested emphasising the role of health professionals in the guideline development process and their contributions in each step. The patients and the public panel members suggested emphasising the importance of clinical guidelines to patients, their families, and the public, along with the role they could play in the guideline development process.

Based on feedback, the project team refined the course outline and topics included. For both groups the topics were broadly similar and proposed topics included:

- introduction to the online learning course
- introduction to clinical guidelines, including definitions, use, and importance
- overview of the development process, and the value the learner could bring
- formation of the GDG and ways of working
- reviewing evidence systematically, and assessing certainty of evidence
- types of recommendations, and moving from evidence to recommendations

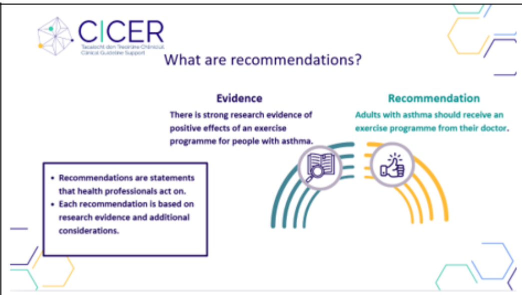
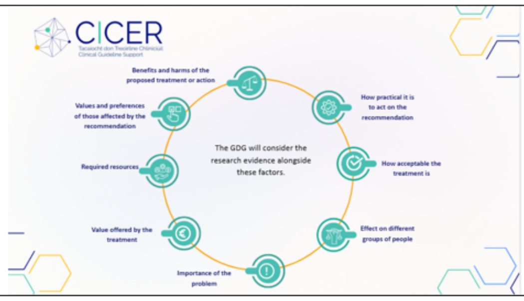
- planning for implementation and analysing budget impact
- disseminating, implementing and updating clinical guidelines.

3.2 Storyboarding phase

After incorporating the feedback of the Advisory group and the panels, detailed content outlines for each online learning course were developed. Initially, the team had envisaged that the patient and public online learning course would be a plain-language version of the health professionals' course. However, after working with the panels, it became clear that each audience had unique reasons for becoming involved in guideline development and differing knowledge needs. From that point forward, bespoke content was developed for each group. While the overarching concept was similar across the two online learning courses, the way the content was presented differed. For example, the online learning course designed for health professionals included technical aspects of systematic review, recommendation development, and planning for implementation. On the other hand, the online learning course designed for the patients and the public was developed in plain language, and incorporated real examples, storytelling, and the use of analogies.

Interactive features such as flashcards, hotspots, learning exercises including knowledge checks and open-ended questions were also planned in the storyboarding phase. The panel members shared the importance of incorporating different learning styles for an effective learning experience. A voiceover script was developed instead of relying on a text-based delivery, with each module narrated by a different person to represent a diversity of voices. Based on the script, visuals were drafted. The visuals used a variety of imagery to portray the information. The script and the visuals together made up the visual storyboards (Figure 3). The visual storyboards detailed how the slides would look, any interactive learning method used, and the script for the voiceover. Along with the visual storyboards, the team circulated ideas for the content of the micro-learning videos, and scripts and visuals were drafted accordingly.

Figure 3: Example of a draft storyboard

2.	 CICER Tacaíocht don Treoirlíne Chliniciúil Clinical Guideline Support What are recommendations? **Evidence** There is strong research evidence of positive effects of an exercise programme for people with asthma. **Recommendation** Adults with asthma should receive an exercise programme from their doctor. • Recommendations are statements that health professionals act on. • Each recommendation is based on research evidence and additional considerations.	Let's revisit the example from earlier on, about whether or not an exercise programme helps those with asthma. Let's say, after the review, the review team found strong research evidence of the positive effects of an exercise programme for people with asthma. The review team is also highly confident in the research findings. In this case, the guideline development group might now be considering including a recommendation like "Adults with asthma should receive an exercise programme from their doctor". The GDG will develop other recommendations following the same process for each question. There are different frameworks GDGs can use to help shape the discussions on different considerations. One of the most commonly used is the "GRADE Evidence to Decision" Framework, which covers many factors to be considered and is used internationally.
3.	 CICER Tacaíocht don Treoirlíne Chliniciúil Clinical Guideline Support The GDG will consider the research evidence alongside these factors. Benefits and harms of the proposed treatment or action How practical it is to act on the recommendation How acceptable the treatment is Effect on different groups of people Importance of the problem Value offered by the treatment Required resources Values and preferences of those affected by the recommendation	While research evidence is very important when developing each recommendation, it's not the only aspect to consider. The GDG will also consider other important issues like: • Benefits and harms of the proposed treatment or action • Values and preferences of those affected by the recommendation • Required resources to put the recommendation into action • The value offered by the treatment, meaning how effective it is considering how much it costs

Storyboards were circulated to the respective panels for feedback and discussion. The members of the health professional panel shared their feedback by email and annotations within the document. The patient and public panel provided their written online feedback on the storyboards, as well as through two online meetings. In these meetings, the project team and the panel members discussed the content, terminology, graphics, and interactive features.

All feedback was incorporated into the storyboards to create final versions of the storyboards. The final versions of the visual storyboards were then used to build the online learning courses and the micro-learning videos.

3.3 Building and testing

Based on the respective sets of storyboards, the courses were built on Articulate, an online learning development software, in an iterative manner. The project team professionally recorded videos of people sharing their experiences of working in GDGs, planning for implementation, and the real-life impact of clinical guidelines.

After a round of internal user-testing, drafts of the learning materials were circulated to the respective panels. The patient and public panel initially received two modules to review, and their feedback was applied to the building of the rest of the modules. Panel members then received all modules and were asked to provide their feedback. Three patient and public panel members provided quantitative feedback on the System Usability Scale(16): they rated the usability of the course at 79.2/100, suggesting a "good" user experience.

Both courses were checked for accessibility through keyboard and using a screen reader. The project team critically assessed the features of the course against technical specifications for online learning courses. The health professionals' course was submitted for formal quality assurance to be hosted on HSeLanD, the HSE's national online learning and development portal. Before publication, the final versions of the courses will be shared with the respective panels. Final materials will be prepared for hosting on the HIQA website and HSeLanD.

Parallel to the building of the online learning course, the team worked with the Communications and Stakeholder Engagement team at HIQA to develop the micro-learning videos in Canva. To align with the look and feel of the online learning course, similar graphics were used in the videos. Drafts of the videos were shared with the panels for feedback. The feedback received was incorporated and the videos finalised.

3.4 Deployment and dissemination

The online learning courses and micro-learnings will be launched in March 2026. The patient and public online course will be deployed on the HIQA website and the health professionals' online course will be deployed on both the HIQA website and HSeLanD. The micro-learning videos will be hosted on the HIQA website and HIQA's YouTube channel. All materials will be free to access.

A press release and social media posts will be designed for the launch of the materials. We will share the materials with our target groups via the following channels:

- project advisory group, patient and public panel, and health professional panel
- CEU and NCEC
- Health Service Executive librarians and guideline methodologists
- patient advocacy groups
- health professional groups
- universities

- the CICER homepage and CICER Patient and Public Involvement (PPI) panel.

The reach of the materials will be measured in the short-term by the extent of media and social media engagement, and in the longer term by the number of individuals accessing the materials. They will be hosted on the HIQA webpage and HSeLanD to ensure longevity and a broad audience. The materials will be reviewed on an annual basis and refreshed as needed, with periodic re-sharing on social media and other channels. We anticipate international interest in the materials and will make the development files available to any international partners that would like to adapt our work for non-profit purposes in their country.

4 Conference

A key deliverable of this project was a one-day knowledge exchange conference. The event was hosted on 23 October 2025 at the Ashling Hotel Dublin and online, by the CICER team in collaboration with Dr. Barbara Clyne from Royal College of Surgeons Ireland (RCSI) University of Medicine and Health Sciences' Department of Public Health and Epidemiology. The conference was developed with key input from patients, health professionals, and subject matter experts in health decision-making, clinical guideline development, and health technology assessment. The conference focussed on the ecosystem of health decision-making in Ireland and the role of stakeholders, with a special emphasis on patients, the public, and health professionals. Here we present on the process for developing the conference and summarise related outputs and outcomes.

4.1 Development of programme, preparation, and advertisement

4.1.1 Programme development

The conference was planned and delivered collaboratively by the CICER team and Dr. Barbara Clyne along with input from advisory group members and stakeholder panels. This co-production approach ensured that patients and the public, health professionals, and experts in health decision-making shaped the content and delivery of the workshop. The theme of the conference, *"Our healthcare system, our voices: an evidence-based approach for healthcare"*, was selected to encourage discussion on inclusiveness and reflect on the role of stakeholders in health decision-making. Its aim was to embrace wider voices that shape evidence-informed decision making, such as clinical guidelines. The event was designed to balance informational and interactive components, by including national and international speakers, roundtable discussions, panel discussions, brief presentations by the research team, an online attendance option, and time and room for networking at a non-academic venue.

Speakers were selected to provide a balance of perspectives across lived experience, clinical practice, and health system leadership. These included:

- Dr Colm Henry, consultant geriatrician and Chief Clinical Officer of the HSE since April 2018. His previous roles include National Clinical Advisor and Group Lead for Acute Hospitals from 2014 to 2018, National Lead for the Clinical Director Programme from 2012 to 2014 and Clinical Director of the Mercy University Hospital, Cork from 2009 to 2012.
- Professor Mary Horgan, the interim Chief Medical Officer of Ireland and a professor of infectious diseases. She has served as Dean of the Medical School at University College Cork and two terms as President of the Royal College of Physicians of Ireland. Professor Horgan has held several national leadership roles, including Chair of Ireland’s first National Research Ethics Committee, membership of the National Public Health Emergency Team and the COVID Advisory Group, Chair of the Expert Group on Rapid Testing, and Chair of the Expert Steering Group on Emerging Health Threats Preparedness.
- Dr. Helen Bulbeck, Founder and Director of brainstrust, a UK-based charity supporting thousands of brain cancer patients. She brings a unique 360-degree perspective as both patient and caregiver and has extensive experience in PPI in guideline and policy development.
- Dr Danielle Pollock, an evidence synthesis expert, lived experience researcher, and Research Fellow at JBI, University of Adelaide. She coordinates the JBI Scoping Review Network and plays a leading role in advancing global methodological standards for evidence synthesis. Her work combines academic expertise with lived experience in evidence-based healthcare.

4.1.2 Preparation

The planning and delivery of the conference were guided by the project advisory group and stakeholder panels, as well as the PPI panel from Dr. Clyne’s research programme. These groups were engaged early to shape the event’s objectives, identify priority topics, and advise on suitable keynote speakers. Their input informed the selection and invitation of speakers, ensuring the programme reflected diverse perspectives and addressed real-world needs. The patient partner co-investigator substantially assisted the team in refining session formats, selecting speakers, and finalising the agenda. Regular check-ins ensured that speakers were supported throughout the preparation process and that their contributions aligned with the conference goals.

The Ashling Hotel Dublin was chosen for its accessibility, proximity to public transport, capacity, and suitability for hybrid delivery. The team coordinated room layouts, audio-visual requirements, signage, and technical support for livestreaming. The morning session was to be livestreamed, enabling participants to join remotely if unable to attend in-person. A restoration area was provided at the back of the room to facilitate privacy for attendees with medical breaks or other needs.

Figure 4: Flyer for conference

CONFERENCE

OUR HEALTHCARE SYSTEM, OUR VOICES: AN EVIDENCE-BASED APPROACH FOR HEALTHCARE

If you are posting on social media, please tag us using the contacts below

@HIQA
@hiqa.bsky.social
Instagram: higaireland

@RCSI_PopHealth
populationhealth@rcsi.ie
@rcsipophealth.bsky.social

If you have comments or feedback on the day, please contact:
Shibu Shrestha
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PROFESSOR MARY HORGAN
Chief Medical Officer
@profmaryhorgan

DR DANIELLE POLLOCK
Lived experience researcher and methodologist
@daniellepollock.bsky.social

4.1.3 Advertisement and outreach

A comprehensive communications strategy was implemented in partnership with HIQA Communications and Stakeholder Engagement team and advisory group members to advertise the event (Figure 4). The promotional campaign emphasised inclusivity to ensure representation from patients, the public, health professionals, and decision-makers. The event was advertised through the following channels:

- HIQA social media, RCSI social media, and CICER webpage.
- Eventbrite registration page for streamlined sign-up.
- Press release distributed through HIQA and partner networks.

Targeted outreach was made to the following:

- Patient organisations via IPPOSI and PPI Ignite.
- Health professional networks and HRB-Trials Methodology Research.
- Diverse stakeholders across healthcare, academia, and policy sectors.

The event reached full capacity within three days, reflecting strong interest across stakeholder groups. To accommodate demand, a waitlist was implemented through Eventbrite, to maximise attendance. Additionally, the online option for the morning session was re-advertised to encourage remote participation for those unable to attend in-person.

4.2 Attendance

4.2.1 Numbers registered and attendance

The conference demonstrated significant interest and engagement across all stakeholder groups invited, reflected in the high registration numbers and strong attendance both online and in-person. Total attendees on the day were as follows:

- 65 participants in person
- 135 participants online
- 200 participants overall.

The event was live-streamed online for the morning session, with online attendees staying an average of 2 hours and 15 minutes for the 2.5-hour livestreaming event, indicating high engagement with the content.

4.2.2 Stakeholder representation

The event brought together voices from patient advocacy, clinical practice, research, and policymaking. There was a strong and diverse representation from key stakeholder groups on the day, which included delegates from:

- patient advocacy groups, including those focussed on dementia, neurological disorder, kidney disease, cancer, and migrant health
- the HSE and Department of Health.
- regulatory bodies, namely HIQA and NCPE
- research institutions, namely four universities and a funder
- health professional organisations, namely pharmacy and general practice
- private sector, including care providers, industry, and media.

Based on registration data, attendees identified as:

- 42.9% researchers
- 27.3% other health professionals
- 16.9% patient or people using services
- 9.1% speakers

- 7.8% clinicians
- 6.5% members of the public
- 2.6% carer or support person.

Note: Percentages exceed 100% as some participants identified with multiple perspectives, for example, as both as patient or service user and other healthcare professional.

4.3 Content summary

4.3.1 Opening remarks

Dr Colm Henry, Chief Clinical Officer of the HSE, delivered the opening remarks from a health system leadership perspective. Dr Henry reflected on the evolution of clinical practice, from an era of fewer guidelines, fewer consultants, and experience-driven decisions to today’s emphasis on standardisation and value-based healthcare. He stressed that modern healthcare is about “working with, not talking at patients,” highlighting the shift toward collaborative decision-making and patient involvement in guideline development.

4.3.2 Keynote Presentations

The keynote presentations began with Professor Mary Horgan, Interim Chief Medical Officer of Ireland. In her keynote address “Our HealthCare System, Our Voices: Research Perspective”, Professor Horgan emphasised that health policy must be firmly grounded in evidence, scientific integrity, and cost-effectiveness. She stressed the importance of involving patients throughout the decision-making process, reminding attendees that healthcare affects everyone at some point in life. She also called for proactive engagement with underrepresented patient groups to ensure their voices shape policy and practice. Professor Horgan highlighted initiatives such as the HRB’s role in integrating patient voices into research funding decisions and the PPI Ignite Network, which trains researchers to engage meaningfully with patients. She also pointed to national strategies, including clinical trials oversight and genomic medicine, where enhanced patient engagement is a core priority.

Building on this theme of inclusion, Dr Helen Bulbeck, Director of Policy and Services at brainstrust and co-founder of the charity, shared her perspective as both a cancer patient and caregiver. Her presentation, “The magic of the ordinary: Effective participation in evidence-informed decision making” explored practical strategies for embedding meaningful patient engagement in policy and research. Dr Helen Bulbeck emphasised that meaningful and early stakeholder involvement is essential for bridging the persistent evidence–practice gap and ensuring decisions are informed by lived experience as well as scientific research. She highlighted the challenges of achieving genuine inclusion, such as power imbalances, tokenism and accessibility barriers, and outlined clear principles for effective engagement, including transparency, designing for inclusion, and creating respectful partnerships. Through practical strategies and real-world examples, she demonstrated how intentional, well-resourced participation leads to stronger, more equitable outcomes, reminding the audience that evidence-informed decision-making must centre on people, their stories, and their needs.

To finish the morning keynote presentations, Dr Danielle Pollock, evidence synthesis expert and Lived Experience Researcher at JBI, University of Adelaide, examined the shared challenges and potential collective solutions in her talk. Her presentation “Embedding Lived Experience in Evidence: Shared Challenges and Collective Solutions” highlighted innovative approaches to patient and public involvement and shared lessons from projects such as Project ENGAGE and the MND Guideline Development. Some of the take-home messages from Dr. Pollock’s presentation included:

- engage early and foster meaningful connections
- people want to be involved; barriers must be removed
- lived experience adds real value to research and guideline development
- those with lived experience are more than their worst moments.

Pictured L-R: Dr Colm Henry and HIQA CEO Angela Fitzgerald; Angela Fitzgerald, Prof Mary Horgan and Dr Máirín Ryan.

4.3.3 Afternoon Session

In the afternoon, Dr. Barbara Clyne, Interim Head of Public Health & Epidemiology at RCSI, opened with a short presentation on evidence-based decision-making in Ireland. She discussed the processes and dynamics involved in GDGs and expert advisory groups in Ireland, based on her data collection from over 100 stakeholders over a five-year period. She highlighted that such decision-making groups have a key role in maintaining transparency and building stakeholder trust, as they can ensure that diverse voices are heard and that recommendations are grounded in robust, inclusive processes. Her findings were that most participants in decision-making groups found membership to be worthwhile and beneficial, with a caveat that some individuals were repeatedly “called on by everybody”, which risked overburdening certain people while overlooking others. She shared practical suggestions on how to improve communication, efficiency, and participation in decision-making groups.

Dr. Clyne's presentation was followed by interactive roundtable discussions, where attendees shared ideas on what to "stop, start, and continue" doing to broaden stakeholder involvement in clinical guidelines and health technology assessments. Participants discussed themes within their tables, with each table being facilitated. Themes generated from the roundtable discussions were as follows:

What to Stop:

- Operating in silos that limit collaboration and patient engagement.
- Relying solely on traditional, top-down approaches to guideline development.
- Assuming current processes adequately represent all patient voices.
- Sending large documents without clear engagement steps.
- Complex application procedures that discourage participation.

What to continue:

- Grounding decisions in evidence, transparency, and value for money.
- Encouraging multidisciplinary collaboration across health sectors.
- Maintaining patient involvement as a core element of policy and decision-making.
- Providing feedback loops to show impact and outcomes of involvement.
- Combining data with real-life patient stories to make evidence relatable.
- Improving training for all stakeholders to support meaningful engagement.
- Facilitating participation for non-English speakers through translation and interpretation support.

What to start:

- Reimbursing for PPI to recognise time and effort.
- Use of artificial intelligence tools to create and summarize content for easier understanding.
- Providing multiple options for involvement as a PPI member (for example, plain language summaries).
- Understanding needs, wants, and challenges from the outset for all parties involved.
- Building more effective communication channels between service users, stakeholders, and clinicians (for example, online chat platforms).
- Education on evidence-based decision-making and its processes for patients and stakeholders.
- Starting public consultation earlier in the decision-making process.
- Using GPs and pharmacists to identify suitable PPI representatives.
- Disseminating plain language summaries through more channels and outlets.
- Including visuals to support interpretation of complex information.
- Increasing involvement of nursing and social care professionals in decision-making.

Interactive roundtable group sessions encouraged collaboration and knowledge exchange among participants during the conference.

The roundtable discussions were followed by a panel discussion, moderated by patient partner co-investigator Stacey Grealis and Dr. Barbara Clyne (RCSI). It featured the following panellists:

- Dr. Danielle Pollock (Lived Experience Researcher, evidence synthesis expert and Research Fellow at JBI, University of Adelaide)
- Dr. Helen Bulbeck, (Director of Policy and Services at *brainstrust*)
- Lora Ruth Wogu (Chief Executive Officer, European Sickle Cell Federation)
- Prof. Susan Smith (Professor of General Practice at Trinity College Dublin and Clinical Lead, CICER)
- Dr. Ronan Glynn (Former Deputy Chief Medical Officer, Department of Health).

The panel discussed a variety of topics, including fostering open dialogue on patient collaboration, embedding patient and public involvement within national policy, strengthening patient partnerships, and advancing the concept of living guidelines to ensure adaptability and relevance over time.

Panel discussion featuring (L-R) Stacey Grealis, Dr. Danielle Pollock, Dr. Ronan Glynn, Lora Ruth Wogu, Prof. Susan Smith, Dr. Helen Bulbeck, Dr. Barbara Clyne.

The afternoon session was rounded out with a presentation by Shibu Shrestha, health technology assessment analyst from HIQA, titled "Co-producing online learning materials on clinical guideline development process: The STAKEholder project”. This presentation highlighted the co-production approach to creating accessible online learning resources that support understanding and engagement in clinical guideline development. This presentation highlighted the forthcoming learning materials being developed within the current project.

4.4 Closing reflections

Closing the event, Angela Fitzgerald, Chief Executive Officer of HIQA, reinforced the core message: meaningful patient involvement is essential to shaping clinical guidelines that deliver efficient and consistent care. Summing up the ethos of evidence-based practice, she reminded attendees that it is vital to “give facts, not feelings.”

4.5 Conference outcomes

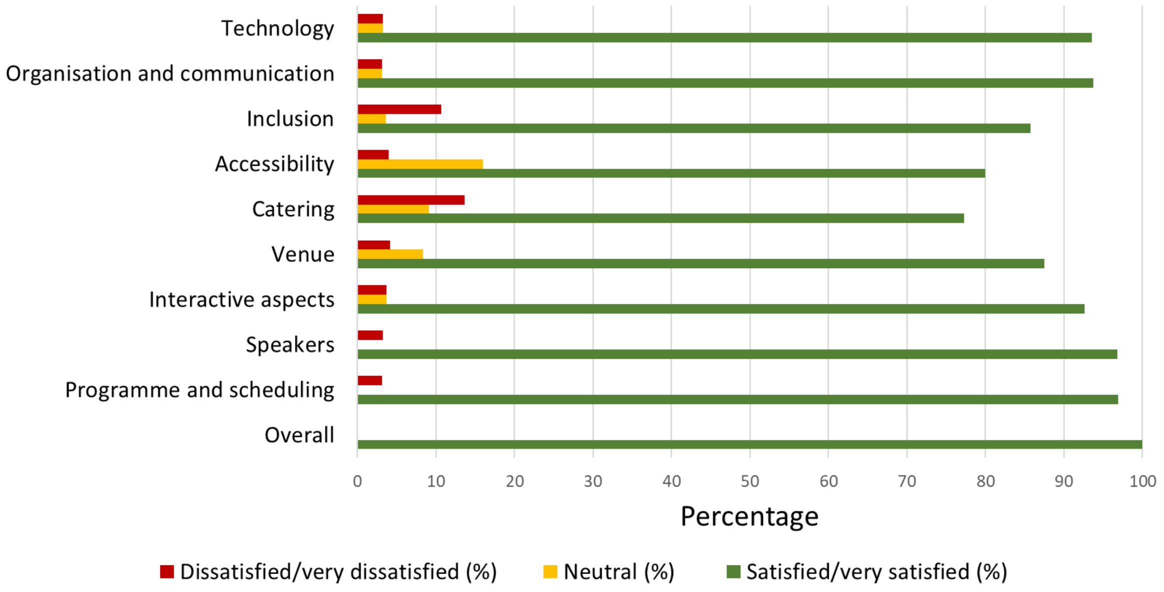
4.5.1 Survey outcomes

To evaluate the impact and effectiveness of the conference, feedback was gathered through an online evaluation form. A ‘quick response’ code was shared with attendees on the day of the conference and was recirculated to attendees by email after the event as a reminder.

A total of 32 people submitted a conference evaluation form, 19 of whom had attended in person and 13 of whom had attended online. Participant satisfaction is illustrated in Figure 5. All respondents were “satisfied” (n=6/32, 19%) or “very satisfied” (n=26/32, 81%) with the event overall. In terms of the different domains, participants were most satisfied with “Speakers” (n=30/31, 96.8%) and “Organisation & Communication” (n=30/32, 93.8%), while satisfaction was slightly lower for the domains “Catering” (n=17/22, 77.3%) and “Accessibility” (n=20/25, 80.0%). As some respondents did not answer all items, the denominator for individual items varied.

In the open-ended questions, participants were asked what aspects of the conference they found most valuable and what key takeaway they would bring forward. Participants highlighted networking, learning from expert speakers, and interactive discussions as the most valuable aspects of the event.

Figure 5: Participant satisfaction with knowledge exchange conference



> *"Really good variety of speakers and topics"*
>
> *"The opportunity to hear personal experiences and learning from members of the guideline development group."*
>
> *"Networking and collaboration opportunities were excellent."*

For key takeaways, participants emphasised gaining practical insights into patient involvement and research processes:

> *"Understanding how to include patient input at the formulation stage and the role of research in shaping practice."*
>
> *"Learning strategies for applying patient involvement in real-world healthcare settings."*

When asked if there was anything we could have done to improve their experience, participants focused on suggestions, such as allowing more time for discussion and networking, improving catering options, and providing clearer pre-event communication and information.

4.5.2 Additional impacts

The conference received an independent write-up in the Irish Pharmacy Union's (IPU) December 2025 edition of the IPU Review (Figure 6). The three-page report was written by Yasmin Aminou, a Pharmacy student at Trinity College Dublin, and covers aspects such as the importance of lived experience in health decision-making, the importance of diversity of voices, and the upcoming learning materials for clinical guideline stakeholders. LinkedIn updates during the day of the conference received a total of 227 reactions, and a write-up of the project on LinkedIn welcomed it as a "significant development" and "worth the effort".

Figure 6: Irish Pharmacy Union Review

Professional
Yasmin Aminou, 4th year Pharmacy Student, Trinity College Dublin

HIQA conference report: *Our Healthcare System, Our Voices*

A recent HIQA conference discussed an evidence-based approach to healthcare, with contributions from many renowned speakers on a range of issues, including the role of Health Technology Assessments and Expert Advisory Groups.

On 23 October, the Health Information and Quality Authority (HIQA) hosted the conference, 'Our Healthcare System, Our Voices: An Evidence-Based Approach for Healthcare', at the Ashling Hotel in Dublin. Over 200 participants attended in person and online.

The conference highlighted the growing role of evidence-based approaches in shaping healthcare, with particular emphasis on clinical guideline development and Health Technology Assessments (HTA). As Ireland's health system faces increasing demands, HTAs have become a key tool for ensuring that new technologies and treatments deliver both clinical benefit and value for money. A key part of this process, emphasised during the event, is recognising the importance of involving patients and stakeholders in these decisions.

From traditional to value-based care

Opening the conference, Dr. Colm Henry, HSE Chief Clinical Officer took attendees through the evolution of clinical practice in Ireland.

58 **IPU Review** December 2025/January 2026

Conference organisers: Pictured from left to right – Cordelia McGeown, Stacey Grealis, Michelle O' Neill, Celine Larkin, Máirín Ryan, Shibu Shrestha, Barbara Clyne, Ruth Martin and Debra Spillane

5 Reflections and Outcomes

5.1 Lessons learned

The experience of the knowledge translation award was extremely valuable and impactful for the CICER programme. It led to several “lessons learned” for the project overall, the conference, and the learning materials.

During the project, it became clear how important it was to “meet people where they are”. That meant starting by asking what stakeholders hope for and what they expect, in terms of both processes and outcomes. In addition to establishing a shared understanding, this also meant tailoring and adapting as the project progressed. It was important that stakeholders felt prepared and empowered to contribute, this included providing additional training and support where needed. It was also important to reimburse stakeholders for their contributions, and to make materials and events free at the point of access. It was important to build trust with our panels and to be as responsive as possible, while also working to complete the project in a timely way to a high standard.

There were several learnings that were particular to the conference event. The hybrid nature of the event allowed us to triple the attendance numbers in comparison to in-person alone. However, the online modality was not as interactive as the in-person one, future hybrid events should be designed to maximise interactivity regardless of modality. Although the venue was technically accessible, the entrance for those using wheelchairs was separate; in future, we would distinguish between a venue that was technically accessible versus one that provided an equitable experience regardless of mobility.

There were also several learnings that were particular to the learning materials. Because of the content expertise required and the anticipated iterative engagement with two diverse target groups, we decided to produce the learning materials in-house to remain responsive and flexible. We had initially intended that the patient and public version of the online learning course would be a plain language version of the health professional online learning course, but it became clear that the two groups had very different needs, perspectives, and baseline knowledge. We also adopted flexible means of providing input, from meetings and calls to review links, online surveys, and shared word documents. This allowed us to elicit rich actionable input from our insightful panels.

5.2 Outputs of the project

The primary outputs of this project are the online learning courses for patients and the public and for health professionals respectively, along with the two micro-learning videos. These will be invaluable resources for patients and health professionals in existing and prospective guideline groups, and for patients and health professionals interested in getting involved in guideline development. They may also prove useful as templates for national partners outside of guideline development and international partners within guideline development.

CICER staff co-presented an oral presentation with our patient partner at the Guidelines International Network conference in Geneva in September 2025 on the co-production approach used in this project. Poster presentations about the project were presented at the Structured Population Health, Policy and Health Services Research Education conference in Dublin in February 2026 and accepted for the Health Technology Assessment International conference in June 2026. We have also submitted an abstract on the outcomes of this project to the Guidelines International Network conference for 2026.

5.3 Impacts of the project

Beyond creating legacy learning materials to support effective PPI, the knowledge translation award has had several positive impacts on the CICER programme. It has helped us to develop a roadmap for conducting meaningful patient and public involvement, for example by providing templates, ways of working, and reimbursing processes for panel members. It has strengthened our collaboration with our patient partner co-investigator and has helped us to connect with patient and professional organisations nationally. By co-hosting a conference with RCSI and hosting a Master of Science in Public Health student placement from University of Limerick, it has also strengthened our ties with the third-level sector. The project has raised our profile internationally: presenting the project at the Guideline International Network conference precipitated an invitation for our patient partner co-investigator to join the

Guideline International Network Patient and Public Involvement working group and prompted our invitation to Dr. Pollock as an international speaker at our knowledge exchange event.

In the longer term, we hope that the current project will lead to a lasting change in how patients, the public, and health professionals are involved in the clinical guideline development process. Their perspectives are invaluable; we must prioritise outreach and preparation so that participants feel welcomed and included in the guideline space and empowered to be meaningfully involved.

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