



## BRINGING PATIENTS AND SOCIETY BACK INTO THE SOCIAL ACCOUNTABILITY OF A MEDICAL SCHOOL

A project intended to help UBC, and other Canadian medical schools engage directly with the public and patients to fulfill their mandate of social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve.

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## Patient & Public Engagement: A Review of Practical Guides

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# REPORT 1

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To access the report, visit:

<https://meetingofexperts.org/programs-activities/social-accountability/>





## Bringing Patients and Society Back into the Social Accountability of a Medical School

### Project Reports

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| Report 1 | Patient and Public Engagement: A Review of Practical Guides  | Created by: Cathy Kline, Patient & Community Partnership for Education   |
| Report 2 | An Environmental Scan of Methods for Patient and Public Engagement   | Created by: Jordan Williams-Yuen, 4 <sup>th</sup> Year Medical Student   |
| Report 3 | Special Considerations: Bringing Indigenous Patients and Public into the Social Accountability of Our Medical School | Created by: Alicia Liang, 4 <sup>th</sup> Year Medical Student   |
| Report 4 | Patient and Public Consultations   | Created by: Angela Towle & Cathy Kline, Patient & Community Partnership for Education and Kenneth Ong & Lucy Wang, 1 <sup>st</sup> Year Medical Students |
| Report 5 | Synthesis Report and Recommendations   | Created by: Angela Towle, Patient & Community Partnership for Education  |

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## Executive Summary

This review of patient engagement practical guides was conducted as part of a project, 'Bringing Patients and Society Back into the Social Accountability of a Medical School' funded by the Royal College of Physicians and Surgeons of Canada. The project is intended to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfill their mandate for social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve. The purpose of the review of practical guides was to identify involvement roles, guiding principles and models for engagement that would be most relevant in the context of medical education and that would form the basis of stakeholder consultations.

We reviewed 30 publicly available patient and community engagement practical guides from Canada, USA, Europe, and Australia with content that could be applicable to health professional education. Most of these guides were designed for health care improvement, health care planning, or health research, but included elements that are relevant to health professional education. Three of the resources we reviewed were developed specifically in the context of health professional education.

Most practical guides defined patient engagement as opportunities for patients and families to participate in decisions about health care design and delivery. Guides shared common guiding principles related to reciprocity, partnership, inclusion, the need for a variety of opportunities for engagement, co-production, communication, supports, and accountability. Most were designed to support a spectrum of involvement, with the International Association of Public Participation (IAP2) among the most popular frameworks. A wide range of engagement tools and techniques were put forward to support different kinds of engagement along a continuum of engagement. Although the need to recruit from diverse groups was highlighted, specific ways to engage with vulnerable, marginalized, and seldom-heard/hard to reach groups was scarce. Power was rarely discussed.

Patient and public engagement in medical education could build on the principles of engagement found in these resources and develop frameworks that would support broadening engagement to include perspectives from the full spectrum of communities that medical schools aim to serve. Stakeholder consultations should explore principles and models of engagement that will support the inclusion of hard to reach groups and increase the diversity of patients involved medical education. The outcomes could be used to develop guidelines for patient and public engagement in medical education that would help medical schools fulfill their social accountability mandate.

## Introduction

This review of patient engagement practical guides was conducted as part of a project, 'Bringing Patients and Society Back into the Social Accountability of a Medical School' funded by the Royal College of Physicians and Surgeons of Canada. The project is intended to help UBC and other Canadian medical schools to engage directly with members of the public and patients to fulfill their mandate for social accountability: to define and address the priority health concerns of the populations they have a responsibility to serve. The purpose of the review of practical guides was to identify involvement roles, guiding principles and models for engagement that would be most relevant in the context of medical education and that would form the basis of stakeholder consultations.

## Scope

We reviewed 30 publicly available patient and community engagement practical guides from Canada, USA, Europe, and Australia with content that could be applicable to health professional education. Since our research focus is medical education programs at UBC, our starting point was a review of 15 resources from Canada, including seven from BC. We compared these with international examples to identify significant gaps.

## Components relevant to medical education

The following are common components of the guides we reviewed that are relevant to medical education. A practical guide specific to medical education could serve to remind educational institutions of their responsibility to engage patients in education and could include:

1. Rationale - why engage patients? (benefits and desired outcomes)
2. Guiding principles / declaration of values
3. Purpose – who it is for?
4. Scope – contexts it is designed for
5. How it was developed / who contributed?
6. Framework(s) – consider different domains (e.g. classroom, clinic/practice setting, institutional/systems level)
7. 'How to' tips – best practice checklist, recruitment strategies for diversity (addressing power), recognition and remuneration guidelines, engagement tools and techniques
8. Evaluation tools

## Key Drivers and Rationale

Most practical guides identified 'top down' drivers for patient engagement such as accreditation standards and government priorities to make health care systems more efficient and improve patient safety. Social accountability was not language that was used. For example, the [Health PEI Engagement Toolkit \(2016\)](#)<sup>11</sup> from Prince Edward Island states:

“As Health PEI strives towards becoming a high performing health system, the Board of Directors and executive leaders have identified the importance of patient and public engagement as a key priority for the organization.”<sup>11, p. 1</sup>

## Development (who contributed?)

Most guides claim to be developed with input from patients and health care providers. The health professionals involved are often named, or at least described by their affiliations or profession. However, there is little information about the patients who were involved or how their perspectives shaped the guide's development. Some practical guides also included input from 'engagement experts,' although it is not clear what kind of background or qualifications are required for this role. It is therefore difficult to describe patient involvement in the creation of the various guides given the limited information provided. For example, the [CIHR Strategy for Patient-Oriented Research \(2017\)](#)<sup>8</sup> states:

"A consultative process was undertaken to develop this PE Framework. A workshop held in Ottawa on Jan 9th brought together a cross-representation of Canadian patients and patient engagement experts, serving as a pivotal step in the process to identify patients' aspirations for engagement in SPOR. Since that time, CIHR has presented the draft to SUPPORT Unit leads, the SPOR Working Group, and the SPOR National Steering Committee for validation and further input." <sup>8, p.4</sup>

The [AAMC Principles of Trustworthiness \(2021\)](#)<sup>16</sup> document names a variety of "collaborators" with a range of credentials (MDs, PhDs, post-doctoral research fellow, MPH and MBA) and reports that the 10 principles are "endorsed" by community stakeholders. The [AAMC website](#) states,

"Since 2015, the AAMC has produced an annual series of Community Engagement Toolkits in collaboration with our members and their communities. These toolkits provide unvarnished community perspectives on crucial issues and views about how our members can be better partners." <sup>16</sup>

The [Canadian Guide for Engaging Patients in Patient Safety \(2019\)](#)<sup>9</sup> was the result of bringing together patients, government, and 19 organizations responsible for improving patient safety and quality and the national or provincial level. These groups formed an 'Action Team' which developed the guide with the help of a consultant team (One World Inc.). Photographs throughout the guide show what are presumably members of the Action Team and suggest the group may have some limitations with respect to diversity, but again it is difficult to assess given the information provided. The guide states:

"Forty patients and providers from across the country participated in focus groups to help develop the guide's scope and content, including feedback on drafts. Ten patients and providers also participated in a usability pilot to validate the format and provide ideas on how to make the guide easier to use." <sup>9, p.5-6</sup>

## Definitions of Engagement

Most practical guides included definitions of engagement. Definitions of patient engagement commonly made references to opportunities for patients and families to participate in decisions about health care design and delivery. According to the BC-based [Patient Voices Network Guide to Patient Engagement](#),<sup>3</sup> patient engagement is:

"the act of involving the patient and their family in decision-making, design, planning, delivery and evaluation of health services." <sup>3, p.5</sup>

The [AAMC Community Engagement Reflection Guide](#)<sup>16</sup> defines community engagement as:

“an iterative, on-going, long-term investment that is foundational to the work of demonstrating trustworthiness. It’s more than building trust in one project or community interactions, but rather building trust in the organization and in the system.”<sup>16, p.1</sup>

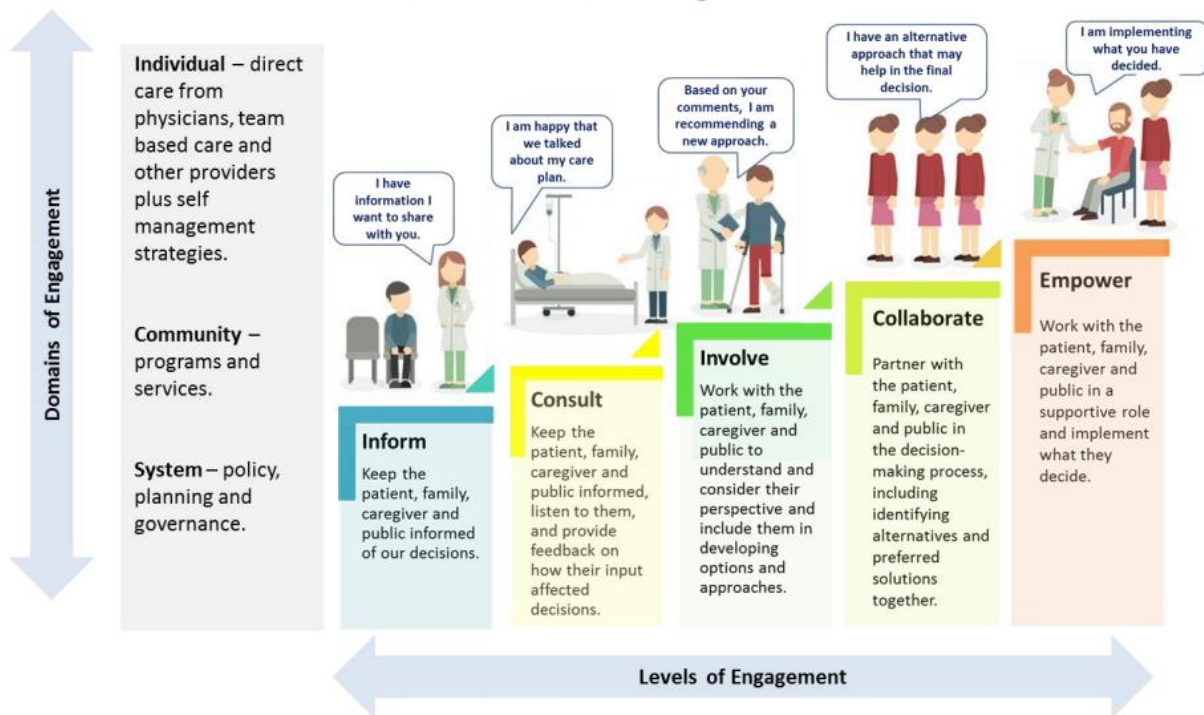
The Health Issues Centre’s [Guide to Engage with Diverse Consumers](#)<sup>28</sup> in Australia says that consumer engagement is:

“an informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or options and undertake collaborative decision making, sometimes as partners.”<sup>28, p. 4</sup>

## Frameworks

Most, but not all, practical guides, included a framework. Practical guides from Canada often included a version of the *International Association of Public Participation (IAP2)* which has different levels of engagement (Inform, Consult, Involve, Collaborate, Empower) that are distinguished by increasing involvement in decisions. Some frameworks also include different areas of engagement – individual (direct patient care), community (programs and services), and system (policy, planning, governance). This is reflected in the [BC Ministry of Health Patient, Family, Caregiver and Public Engagement Framework \(2018\)](#)<sup>1</sup> adaptation of the IAP2 framework as follows:

### A Multi-Dimensional Health Sector Engagement Framework for Patients, Families, Caregivers and the Public



This spectrum is adapted from the International Association for Public Participation (IAP2), a well-known model and the continuum outlined in the report from the B.C. Office of the Auditor General, “Public Participation: Principles and Best Practices for British Columbia.”

## Guiding Principles

Most practical guides had a set of guiding principles for engagement. These included themes related to respect, trust, inclusivity, reciprocity, co-production/co-design, partnership and shared decision making (“nothing about us, without us”), communication, transparency and accountability/responsiveness. The AAMC Principles of Trustworthiness are particularly noteworthy for working with historically marginalized groups in the context of medical education. We identified a set of common principles across practical guides. We presented these principles to participants in the patient and public consultations we conducted as part of our project to get their feedback on their importance for engaging with a medical school. These principles are:

### **Reciprocity**

Relationships are mutually beneficial, based on trust and mutual respect.

### **Partnership/ shared decision making**

University and community partners have equal voices and share power to make decisions.

### **Inclusion**

Diverse perspectives are sought and invited to participate. Engagement processes are accessible.

### **Different levels of engagement**

There are multiple opportunities for community to engage in medical education (from classroom to committees).

### **Co-production**

University and community partners work together to co-develop and co-design engagement processes and activities.

### **Two-way Communication**

Communication is open, honest, with clear expectations on both sides.

### **Supports**

Community partners are given the supports and information they need to participate fully.

### **Accountability**

Transparency, shared outcomes, feedback, maintain the relationship.

## Engagement Tools & Techniques

Most resources are designed for health care providers or decision makers to engage patients and families in program planning or quality improvement activities. Resources often include recruitment and screening tips, consultation methods, self-assessment and evaluation tools. A few practical guides included resources for preparing patient / family partners.<sup>4,10,15a</sup> However, these were usually designed as tips for how the health care partner can prepare the patient partner. An exception is the [Patient Advisors Network](#)<sup>15b</sup> which provides tips for ‘how to tell your story’.

Different tools are appropriate for different levels of engagement on the IAP2 spectrum. Common tools for the Inform level include: news releases, podcast, websites, information repository, fact sheet, briefing note, reports, posters, pamphlets, video, open house, mail drop (e-mail or hard copy). Consult techniques might include: surveys, Delphi process, comment form, interviews and focus groups. Involve methods could include: workshops, world café, open space, forum, mapping, site visit, etc. Examples of Collaborate tools include: advisory committees, roundtables, appreciative inquiry, etc. Empower techniques include voting, delegation, think tank, citizen panel, etc.

The Health Issues Centre's [Guide for Inclusive Community Consultations](#)<sup>27</sup> makes a distinction between *inward* facing consultations which are service-centred, designed by health services and conducted by staff at the point of care, versus *outward* facing methods which are designed in collaboration with communities, conducted by community members and undertaken in the community.

## Evaluation Tools

Many practical guides include evaluation resources designed to help users evaluate engagement processes and outcomes. The Canadian Patient Safety Institute's [Engaging Patients in Patient Safety](#)<sup>9</sup> Canadian guide is particularly comprehensive, including resources for planning and carrying out evaluation of patient engagement across an organization from point of care and at the organizational level. Other practical guides include sample checklists, surveys, scales, and sample evaluation questions tailored to patients/families and providers/leaders.<sup>10,11</sup>

## Gaps

Most practical guides provided examples of very common community engagement methods. While guiding principles and recruitment point to the need to be inclusive, little attention is paid to methods designed for vulnerable, marginalized or 'hard to reach' groups. A noteworthy exception is the Health Issues Centre [Guide for Inclusive Community Consultations](#),<sup>27</sup> which includes 32 consultation methods for diverse communities such as: aged, young people and children, Aboriginal, cultural and linguistically diverse communities, people in rural areas, people with disabilities and LGBTIQ+ community members. Power was rarely explicitly addressed. A notable exception is the [AAMC Principles of Trustworthiness](#)<sup>16</sup> which takes a justice-oriented approach to the process of engagement with principles grounded in sharing power and expertise informed by 'unvarnished community perspectives'. [Health PEI's Engagement Toolkit](#)<sup>11</sup> includes logistical tips to reduce barriers related to power such as attending to: location of engagement (time and place), capacity of facilitators to build trust, capacity of patients to participate, and methods of engagement.

## Conclusion

Patient and public engagement in medical education could build on the principles of engagement found in these resources and develop frameworks that would support broadening engagement to include perspectives from the full spectrum of communities that medical schools aim to serve. Stakeholder consultations should explore principles and models of engagement that will support the inclusion of harder to reach groups and increase the diversity of patients involved medical education. The outcomes could be used to develop guidelines for patient and public engagement in medical education that would help medical schools fulfill their social accountability mandate.



# List of Patient Engagement Practical Guides Reviewed

## BRITISH COLUMBIA

1. **BC Ministry of Health. Patient, Family, Caregiver and Public Engagement Framework 2018.**  
<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/heath-care-partners/patients-as-partners/patients-as-partners-framework.pdf>
2. **BC Ministry of Health. Patients as Partners Initiative. Patient, Family, Caregiver and Public Engagement Planning Guide. 2018.**  
<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/heath-care-partners/patients-as-partners/engagement-planning-guide.pdf>
  - 2a. **BC Ministry of Health. Engagement Planning Summary.**  
<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/heath-care-partners/patients-as-partners/engagement-planning-summary.pdf>
  - 2b. **BC Ministry of Health Patient, Public and Stakeholder Engagement Framework.**  
<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/heath-care-partners/patients-as-partners/engagement-planning-infographic.pdf>
3. **Patient Voices Network. A Guide to Patient Engagement.**  
[https://patientvoicesbc.ca/wp-content/uploads/2019/07/PVN\\_Getting-Started-with-Patient-Engagement\\_WEB.pdf](https://patientvoicesbc.ca/wp-content/uploads/2019/07/PVN_Getting-Started-with-Patient-Engagement_WEB.pdf)
4. **BC Mental Health and Substance Use Services, PHSA. Patient and Family Engagement Framework. [no date but includes references published in 2020]**  
<http://www.bcmhsus.ca/allpageholding/Documents/BCMHSUS%20Patient%20and%20Family%20Engagement%20Framework.pdf>
5. **BC Renal, PHSA. Patient and Family Engagement Framework. June 2019.**  
[http://www.bcrenal.ca/resource-gallery/Documents/Pt\\_Engagement\\_and\\_Family\\_Engagement\\_Framework.pdf](http://www.bcrenal.ca/resource-gallery/Documents/Pt_Engagement_and_Family_Engagement_Framework.pdf)
6. **Fraser Health. Community Planning Tool. Applying a Health Equity Lens to Program Planning. 2018.**  
[https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Topics/20180322\\_Community\\_Planning\\_Tool\\_Online.pdf](https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Topics/20180322_Community_Planning_Tool_Online.pdf)
7. **University of British Columbia UBC Health. Patient Engagement in Education in UBC Health Programs. 2018.**  
[https://health.ubc.ca/sites/health.ubc.ca/files/documents/Patient%20Engagement%20in%20Education%20Report\\_April2018\\_cover.pdf](https://health.ubc.ca/sites/health.ubc.ca/files/documents/Patient%20Engagement%20in%20Education%20Report_April2018_cover.pdf)

## CANADA

8. **Canadian Institutes of Health Research. Strategy for Patient-Oriented Research. Patient Engagement Framework. 2014.**  
[https://cihr-irsc.gc.ca/e/documents/spor\\_framework-en.pdf](https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf)
9. **Canadian Patient Safety Institute. Engaging Patients in Patient Safety – a Canadian Guide. Patient Engagement Action Team. 2017, last modified December 2019.**  
[https://www.patientsafetyinstitute.ca/en/toolsResources/Patient-Engagement-in-Patient-Safety-Guide/Documents/EngagingPatientsInPatientSafety\\_EN\\_2020.pdf](https://www.patientsafetyinstitute.ca/en/toolsResources/Patient-Engagement-in-Patient-Safety-Guide/Documents/EngagingPatientsInPatientSafety_EN_2020.pdf)
- 9a. **Canadian Patient Safety Institute. How can we make the partnership with patients/families more impactful?**  
<https://www.patientsafetyinstitute.ca/en/toolsResources/Pages/How-can-we-make-the-partnership-with-patients-families-more-impactful.aspx>
10. **Alberta Health Services. A resource toolkit for engaging patients and families at the planning table. 2014**  
<https://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf>
11. **Health PEI. Engagement Toolkit. Revised March 2016.**  
[http://www.gov.pe.ca/photos/original/hpei\\_engagetool.pdf](http://www.gov.pe.ca/photos/original/hpei_engagetool.pdf)
12. **Health Quality Ontario. A list of Ontario Health Care Acronyms for Patient and Caregiver Advisors**  
<https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-tools-and-resources>
13. **Université de Montréal. Collaborative Practice and Patient Partnership in Health and Social Services. Competency Framework. Original French version 2016, English translation 2019.**  
[https://ceppp.ca/wp-content/uploads/2021/01/IPCAndPatientPartnershipCompetencyFramework\\_HealthAndSocialServices-1.pdf](https://ceppp.ca/wp-content/uploads/2021/01/IPCAndPatientPartnershipCompetencyFramework_HealthAndSocialServices-1.pdf)
14. **Université de Montréal. Recruitment des Patients Partenaires. Guide Pratique. 2016.**  
<https://ceppp.ca/en/resources/guide-de-recrutement-des-patients-partenaires/>
- 15a. **Patient Advisors Network. 5 Tips for requesting stories from patients and caregivers.**  
[https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan\\_making\\_stories\\_matter\\_-\\_requester\\_tip\\_sheet.pdf](https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan_making_stories_matter_-_requester_tip_sheet.pdf)
- 15b. **Patient Advisors Network. 5 Tips for responding to a request for your story**  
[https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan\\_making\\_stories\\_matter\\_-\\_advisor\\_tip\\_sheet.pdf](https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan_making_stories_matter_-_advisor_tip_sheet.pdf)

## USA

**16. Association of American Medical Colleges Center for Health Justice. Principles of Trustworthiness**

<https://www.aamchealthjustice.org/resources/trustworthiness-toolkit>

<https://www.aamchealthjustice.org/media/286/download?attachment>

**17. Agency for Healthcare Research & Quality. Working with Patient and Family Advisors.**

[https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1\\_Tool\\_12\\_WkWthAdv\\_HO\\_508.pdf](https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Tool_12_WkWthAdv_HO_508.pdf)

**18a. Institute for Patient- and Family-Centred Care. Patient and Family Engagement Strategies.**

<https://www.ipfcc.org/bestpractices/engagement-strategies-and-definitions.pdf>

**18b. Institute for Patient- and Family-Centred Care. A Patient and Family Advisory Council Workplan: Getting Started.**

[https://www.ipfcc.org/resources/A\\_Patient\\_and\\_Family\\_Advisory\\_Council\\_Workplan\\_Getting\\_Started.pdf](https://www.ipfcc.org/resources/A_Patient_and_Family_Advisory_Council_Workplan_Getting_Started.pdf)

**19a. Patient-Centred Outcomes Research Institute (PCORI). Engagement rubric for applicants. 2014, updated 2015.**

<https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>

**19b. Patient-Centred Outcomes Research Institute (PCORI). Ways of Engaging - Engagement ACTtivity Tool (WE-ENACT).**

<https://www.pcori.org/sites/default/files/PCORI-WE-ENACT-3-0-Patients-Stakeholders-Item-Pool-080916.pdf>

**20. Centers for Medicare and Medicaid Services. Person and Family Engagement Toolkit. April 2021.**

<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Person-and-Family-Engagemen.pdf>

**21. Health Research & Educational Trust. A Leadership Resource for Patient and Family Engagement Strategies. 2013.**

[https://www.aha.org/system/files/hpoe/Reports-HPOE/Patient\\_Family\\_Engagement\\_2013.pdf](https://www.aha.org/system/files/hpoe/Reports-HPOE/Patient_Family_Engagement_2013.pdf)

## EUROPE

**22. National Coordinating Centre for Public Engagement. Introducing the EDGE tool. Self-assessing your support for public engagement.**

[https://www.publicengagement.ac.uk/sites/default/files/publication/introducing\\_the\\_edge\\_tool.pdf](https://www.publicengagement.ac.uk/sites/default/files/publication/introducing_the_edge_tool.pdf)

**23. Smits DW, Klem M, Ketelaar M. The Involvement Matrix. Involvement of patients in projects and research. Practical Guide March 2019.**

<https://www.kcrutrecht.nl/wp-content/uploads/2019/05/Involvement-Matrix-Practical-guide.pdf>

**24. Core Principles for Public Engagement. A collaborative project led by the National Coalition for Dialogue and Deliberation (NCDD), the International Association for Public Participation (IAP2), the Co-Intelligence Institute and other leaders in public engagement. May 2009.**

[www.ncdd.org/pep](http://www.ncdd.org/pep)

**25. Involve and National Consumer Council. Deliberative Public Engagement: Nine Principles. June 2008.**

[https://www.involve.org.uk/sites/default/files/field/attachemnt/Deliberative-public-engagement-nine-principles\\_1.pdf](https://www.involve.org.uk/sites/default/files/field/attachemnt/Deliberative-public-engagement-nine-principles_1.pdf)

## **AUSTRALIA**

**26. Health Issues Centre, Melbourne, Victoria.**

<https://hic.org.au/consumer-engagement-resources-october-2021/>

**27. Guide for Inclusive Community Consultations October 2021**

<https://hic.org.au/wp-content/uploads/2021/10/SCV-HIC-Guide-for-inclusive-community-consultations.-FINAL-1.pdf>

**28. Guide to Engage with Diverse Consumers in Healthcare Partnerships. October 2021.**

<https://hic.org.au/wp-content/uploads/2021/10/SCV-HIC-Guide-to-Engage-with-Diverse-Consumers.-FINAL.pdf>

**29. Consumer Mentorship Program Manual and Consumer Mentorship Guide October 2021**

<https://hic.org.au/wp-content/uploads/2021/10/Consumer-mentorship-program.-Manual-FINAL-with-link.pdf>

<https://hic.org.au/wp-content/uploads/2021/10/Consumer-mentorship-program-Guide-FINAL-with-link.pdf>

**30. Guide for consumers to self-assess the quality of their engagement in healthcare organizations. October 2021.**

<https://hic.org.au/wp-content/uploads/2021/10/Guide-to-assess-own-quality-of-engagement-FINAL.pdf>