



National guideline for supporting the learning, participation, and wellbeing of autistic children and their families

Presented by

Prof Andrew Whitehouse and A/Prof David Trembath
on behalf of the Guideline Development Group

12th July 2022

Acknowledgment of Country

This webinar is being recorded and will be available via the Autism CRC website

We warmly welcome questions

- Please use the question function
- Where more than one question relates to the same issue, we will group them when responding
- Where information requested is of a highly technical nature, it will be provided in the Administration and Technical Report

Declaration of Interests

- All members of the Guideline Development Group and Reference Group declared interests (will be published with the Guideline)
- The presenters have no conflicts of interest in relation to this presentation

Overview of webinar

1. Acknowledgements
2. What is a Guideline?
3. Why is a Guideline needed?
4. How is the Guideline being developed?
5. How do you provide feedback?
6. Q&A

Acknowledging language preferences

- We warmly acknowledge that different people have different preferences regarding language used to talk about autism
- In the Guideline (and all related documents and activities), we use **identify-first language** based on evidence collected as part of the community consultation that identity first language **was both preferred and acceptable** to a large majority of respondents.

What do we mean by these terms?

Supports

Any paid activity performed by a practitioner that seeks to improve a person's experience of the world, either through helping the child acquire skills that promote their learning, participation and wellbeing, empowering parents to support and advocate for their child and promote their own and their family's wellbeing, and/or create safe and accessible environments that support learning, participation, and child and family wellbeing.

Learning

Acquiring knowledge and skills.

Participation

The involvement in life situations that a person desires and in a way that they agree to.

Wellbeing

Positive and sustainable characteristics, such as being comfortable, healthy, and happy, which help an individual thrive and flourish.

Practitioners

People who are paid to provide support services to children and families.



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Acknowledging Contributions

Children, families, and community

- Children and families who participated in previous research, that we reviewed
- Over 700 people participated in community consultation activities



Research assistants

Name	Discipline/Expertise	Organisation
Briohny Dempsey	Occupational therapy	Telethon Kids Institute
Georgina Earl	Neuroscience	Telethon Kids Institute
Libby Groves	Speech pathology	Griffith University
Emma Hinze	Psychology	Griffith University
Rachelle Wicks	Psychology	Griffith University

Support with preparing community consultation

Name	Organisation
A/Prof Jenny Cartmel	Griffith University
Dr Marilyn Casley	Griffith University
Prof Sharynne McLeod	Charles Sturt University
Dr Emmah Baque	Griffith University
Dr James Best	Junction Street Family Practice
Kelly Clark	University of Western Australia
Georgia Davies	Victoria University of Wellington
Rhiannon Latham	Queensland Department of Education
Antonina Loncarevic	Telethon Kids Institute
Meghan McAnany	Griffith University
Claire Perrozzi	Telethon Kids Institute
Amanda Porter	Personal contribution
Shaun Ruigrok	Personal contribution
Carla Wallace-Watkin	Victoria University of Wellington

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Support in sharing information about the Guideline (e.g., email updates, website) and preparing documents (e.g., graphic design).

- Cally Jackson
- Jason Kotzur
- Darcy Maguire
- Sally Vidler

What is a Guideline?



NHMRC guidelines are intended to promote health, prevent harm, encourage best practice and reduce waste.

NHMRC guidelines are based on a review of the available evidence, and follow transparent development and decision making processes.

They are informed by the judgement of evidence by experts, and the views of consumers, community groups and other people affected by the guidelines.

In regard to ethical issues, NHMRC guidelines reflect the community's range of attitudes and concerns.

Why is a Guideline needed?



The potential benefits of supports

When provided in a **safe, effective**, and way that is **desirable to** autistic children and their families...

Providing autistic children and their families with access to supports during childhood **creates a significant opportunity** to support early development, maximise their participation in activities of childhood, and promote their wellbeing



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The reality

Accessing **safe, effective**, and **desirable** supports can be challenging for a variety of reasons including:

Challenges	Questions Parents and Practitioners ask
The 'maze' of different supports	What is most likely to be safe, effective, and desirable for a particular child and family?
The variety of evidence that must be considered when selecting and delivering supports	What is the best available research evidence? What is the evidence from practice? What are the preferences and priorities of children and families?
Lack of guidance on best practice	Where do parents, practitioners, and policy makers go for sound advice, based on a rigorous consultation and evidence gathering process?

How did the Guideline come about?




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In 2020, Autism CRC took a step towards
addressing these challenges


The Report and Resources



Interventions for children on the autism spectrum: A synthesis of research evidence

Andrew Whitehouse
Kandice Varcin
Hannah Waddington
Rhylee Sulek
Cathy Bent
Jill Ashburner
Valsamma Eapen
Emma Goodall
Kristelle Hudry
Jacqueline Roberts
Natalie Silove
David Trembath


September 2020





Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program

autismcrc.com.au




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Interventions for children on the autism spectrum

A synthesis of research evidence



Autism CRC has published a report for families, clinicians, researchers and policy makers, which synthesises all available high-quality evidence about interventions for children on the autism spectrum.

Interventions for children on the autism spectrum: A synthesis of research evidence

A landmark report for families, clinicians, researchers and policy makers

Evidence shows that effective intervention during childhood plays an important role in promoting learning and participation in everyday life activities. However, navigating the range of interventions can be difficult.

The report, [Interventions for children on the autism spectrum: A synthesis of research evidence](#) (Autism Interventions Evidence Report), provides families and clinicians the best opportunity to make informed decisions when choosing interventions. It includes a broad overview of intervention for children on the autism spectrum, including the principles underpinning all interventions, and the rationale behind each category of intervention. The report also includes a comprehensive review of the scientific evidence for the effects of interventions for children on the spectrum, both therapeutic and otherwise. The evidence review was conducted to international best-practice standards, including only the highest quality of evidence. The report was commissioned by the National Disability Insurance Agency and completed by Autism CRC through the work of a research team with a diverse range of professional backgrounds.

[Register to access the full report](#)

Community summaries

We have prepared community summaries for the two reviews contained within the Autism Interventions Evidence Report:

- Community summary 1:
[Interventions for children on the autism spectrum, and their application in the Australian community \(Narrative review\)](#)
- Community summary 2:
[A review of evidence for interventions for children on the autism spectrum \(Umbrella review\)](#)

Interventions for children on the autism spectrum

A synthesis of research evidence

- [Register to access full report](#)
- Community summaries
 - [Narrative review](#)
 - [Umbrella review](#)
- Category overviews
 - [Behavioural interventions](#)
 - [Developmental interventions](#)
 - [Naturalistic developmental behavioural interventions](#)
 - [Sensory-based interventions](#)
 - [Technology-based interventions](#)
 - [Animal-assisted interventions](#)
 - [Cognitive behaviour therapy](#)
 - [Treatment and Education of Autistic and related Communication-handicapped Children \(TEACCH\) interventions](#)



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<https://www.autismcrc.com.au/interventions-evidence>

The report did three main things

1. Summarised:
 1. The different types of supports (Sandbank et al., 2020)
 2. Different practitioner training pathways in Australia
2. Synthesised the **scientific evidence** for the effects of supports on a range of child and family outcomes
3. *Took an important first step towards the development of a practice guideline*



What did the evidence synthesis contribute?



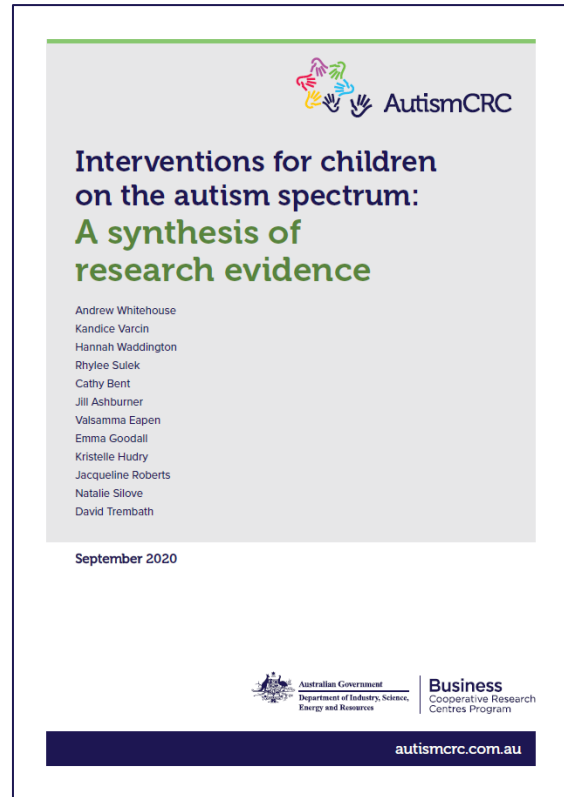
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What was still needed?



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A key recommendation from the report



That a national practice guideline be developed in consultation with the autistic and autism communities

Guideline development commenced in October 2021



The screenshot displays the AutismCRC website. At the top left is the AutismCRC logo, featuring five colorful hands (red, orange, yellow, green, blue) arranged in a circle. To the right of the logo is the text 'AutismCRC'. In the top right corner, there is a 'Connect Hub' link with a user icon and a search bar labeled 'Search Autism CRC'. Below the header is a navigation menu with links: 'Our work', 'Knowledge Centre', 'Get involved', 'News', 'About us', and 'Contact us'. The main content area has a blue header with the title 'Supporting Children National Guideline' in white. Below the title, there is a paragraph: 'Creating a national practice guideline for supporting the development and participation of children on the autism spectrum and their families.' To the right of this text are three small images: a woman and a child looking at a laptop, a woman and a child playing with blocks, and a man and a child reading a book. Below the blue header is a dark blue section with the title 'Supporting Children National Guideline' in white. Underneath this is a white section with the following text: 'Work is currently underway to create a national practice guideline for supporting the development and participation of children on the autism spectrum and their families (Supporting Children National Guideline). The guideline will support families to make informed choices when accessing services, and provide professionals with a set of recommendations to guide ethical and effective service delivery. The recommendations will be based on the best available research and a comprehensive community consultation process. The guideline is being developed according to the National Health and Medical Research Council's recommended process. The guideline will be informed by both the research evidence, building on the [synthesis completed in 2020](#), reviews of previous autism guidelines and the experiences of individuals on the autism spectrum and their families accessing therapy and support services, and a community consultation process, which will begin late February 2022.'

How is the Guideline being developed?

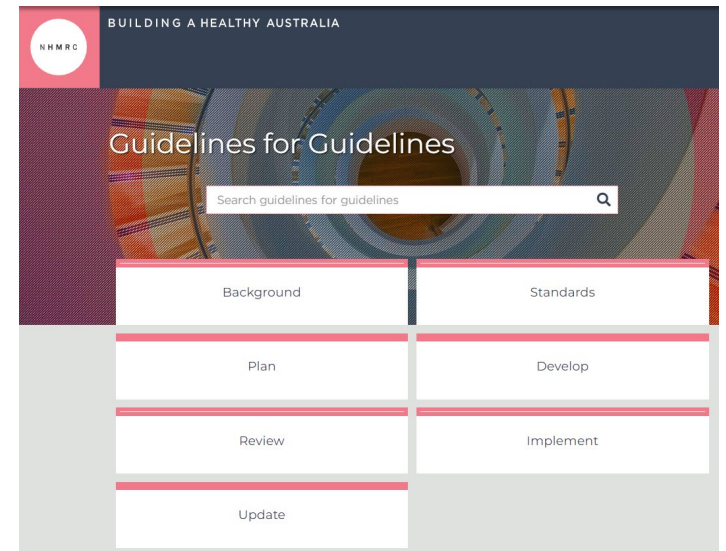
Foundations

- Commissioned by Autism CRC
- Co-developed with autistic people, parents, clinical community, researchers, and broader community
- Meeting NHMRC standards

NHMRC Guidelines for Guidelines

NHMRC Standards for Guidelines:

- Standard 1 - Be relevant and useful for decision making
- Standard 2 - Be transparent
- Standard 3 - Be overseen by a guideline development group
- Standard 4 - Identify and manage conflicts of interest
- Standard 5 - Be focused on health and related outcomes
- Standard 6 - Be evidence informed
- Standard 7 - Make actionable recommendations
- Standard 8 - Be up-to-date
- Standard 9 - Be accessible



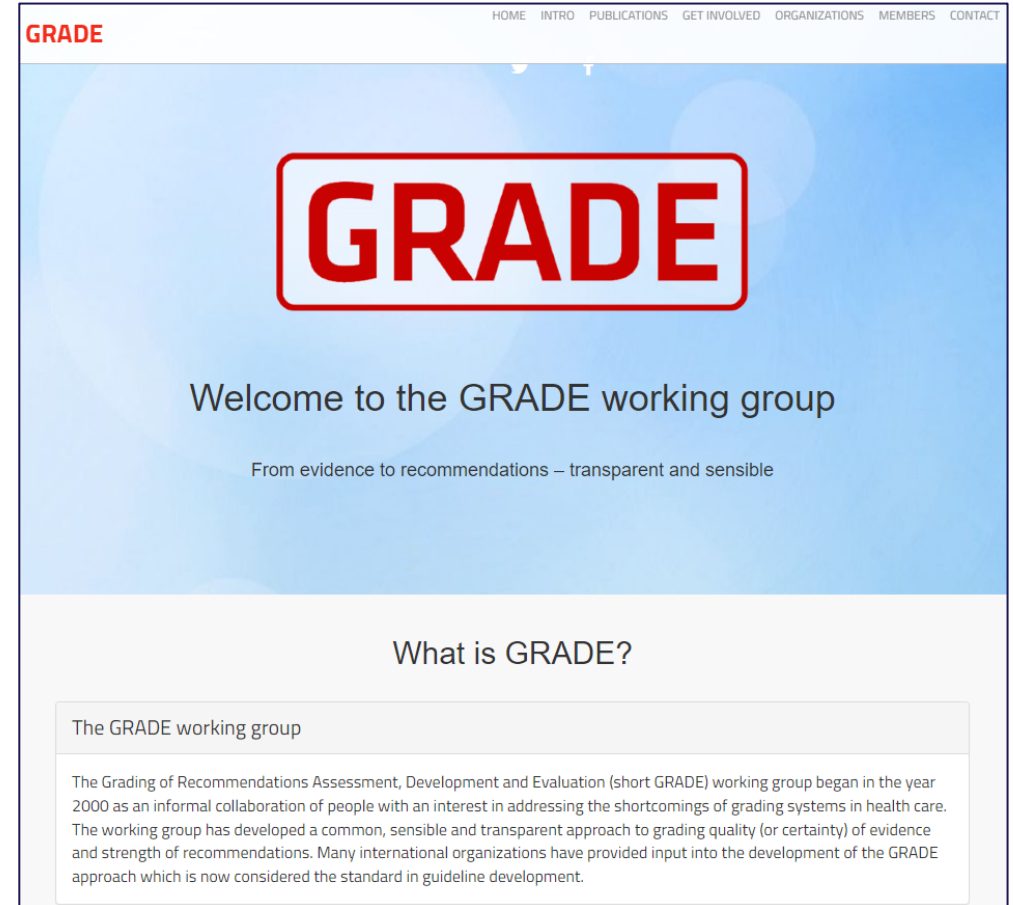
GRADE (Grading of Recommendations, Assessment, Development and Evaluations)

“...A transparent framework for developing and presenting summaries of evidence and provides a systematic approach for making clinical practice recommendations.

It is the most widely adopted tool for grading the quality of evidence and for making recommendations with over 100 organisations worldwide officially endorsing GRADE.”



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<https://bestpractice.bmj.com/info/toolkit/learn-ebm/what-is-grade/>

GRADE

Evidence to Decision Framework



Moberg et al. *Health Research Policy and Systems* (2018) 16:45
<https://doi.org/10.1186/s12961-018-0320-2>

Health Research Policy
and Systems

REVIEW

Open Access



The GRADE Evidence to Decision (EtD) framework for health system and public health decisions

Jenny Moberg^{1*}, Andrew D. Oxman¹, Sarah Rosenbaum¹, Holger J. Schünemann², Gordon Guyatt³, Signe Flottorp¹, Claire Glenton¹, Simon Lewin^{1,4}, Angela Morelli¹, Gabriel Rada⁵, Pablo Alonso-Coello⁶, for the GRADE Working Group

Abstract

Objective: To describe a framework for people making and using evidence-informed health system and public health recommendations and decisions.

Background: We developed the GRADE Evidence to Decision (EtD) framework for health system and public health decisions as part of the DECIDE project, in which we simultaneously developed frameworks for these and other types of healthcare decisions, including clinical recommendations, coverage decisions and decisions about diagnostic tests.

Developing the framework: Building on GRADE EtD tables, we used an iterative approach, including brainstorming, consultation of the literature and with stakeholders, and an international survey of policy-makers. We applied the framework to diverse examples, conducted workshops and user testing with health system and public health guideline developers and policy-makers, and observed and tested its use in real-life guideline panels.

Findings: All the GRADE EtD frameworks share the same basic structure, including sections for formulating the question, making an assessment and drawing conclusions. Criteria listed in the assessment section of the health system and public health framework cover the important factors for making these types of decisions; in addition to the effects and economic impact of an option, the priority of the problem, the impact of the option on equity, and its acceptability and feasibility are important considerations that can inform both whether and how to implement an option. Because health system and public health interventions are often complex, detailed implementation considerations should be made when making a decision. The certainty of the evidence is often low or very low, but decision-makers must still act. Monitoring and evaluation are therefore often important considerations for these types of decisions.

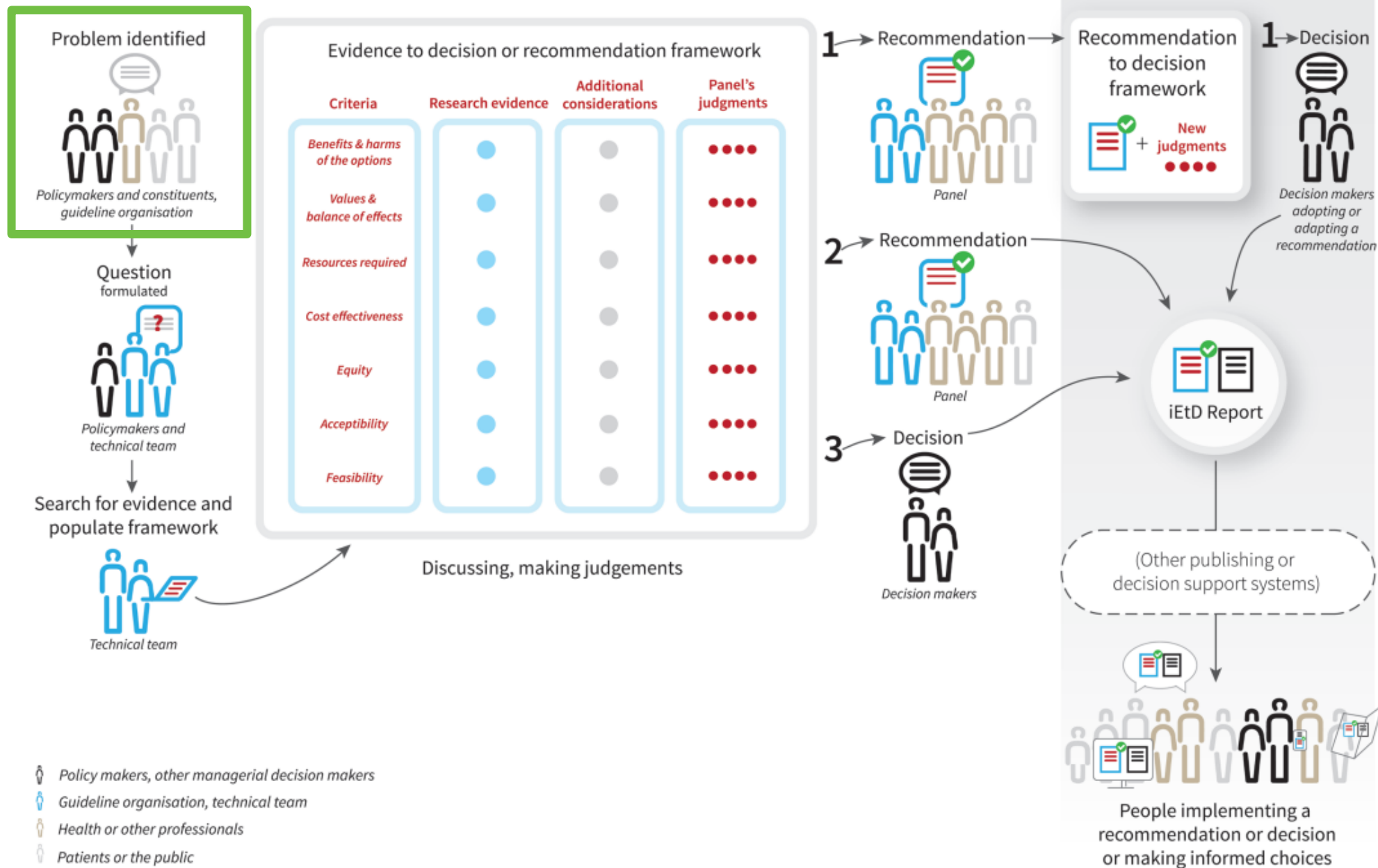
We illustrate the different components of the EtD framework for health system and public health decisions by presenting their application in a framework adapted from a real-life guideline.

Discussion: This framework provides a structured and transparent approach to support policy-making informed by the best available research evidence, while making the basis for decisions accessible to those whom they will affect. The health system and public health EtD framework can also be used to facilitate dissemination of recommendations and enable decision-makers to adopt, and adapt, recommendations or decisions.

Keywords: Decision-making, Health systems, Public health, GRADE, Evidence to decision, Recommendations, Methodology

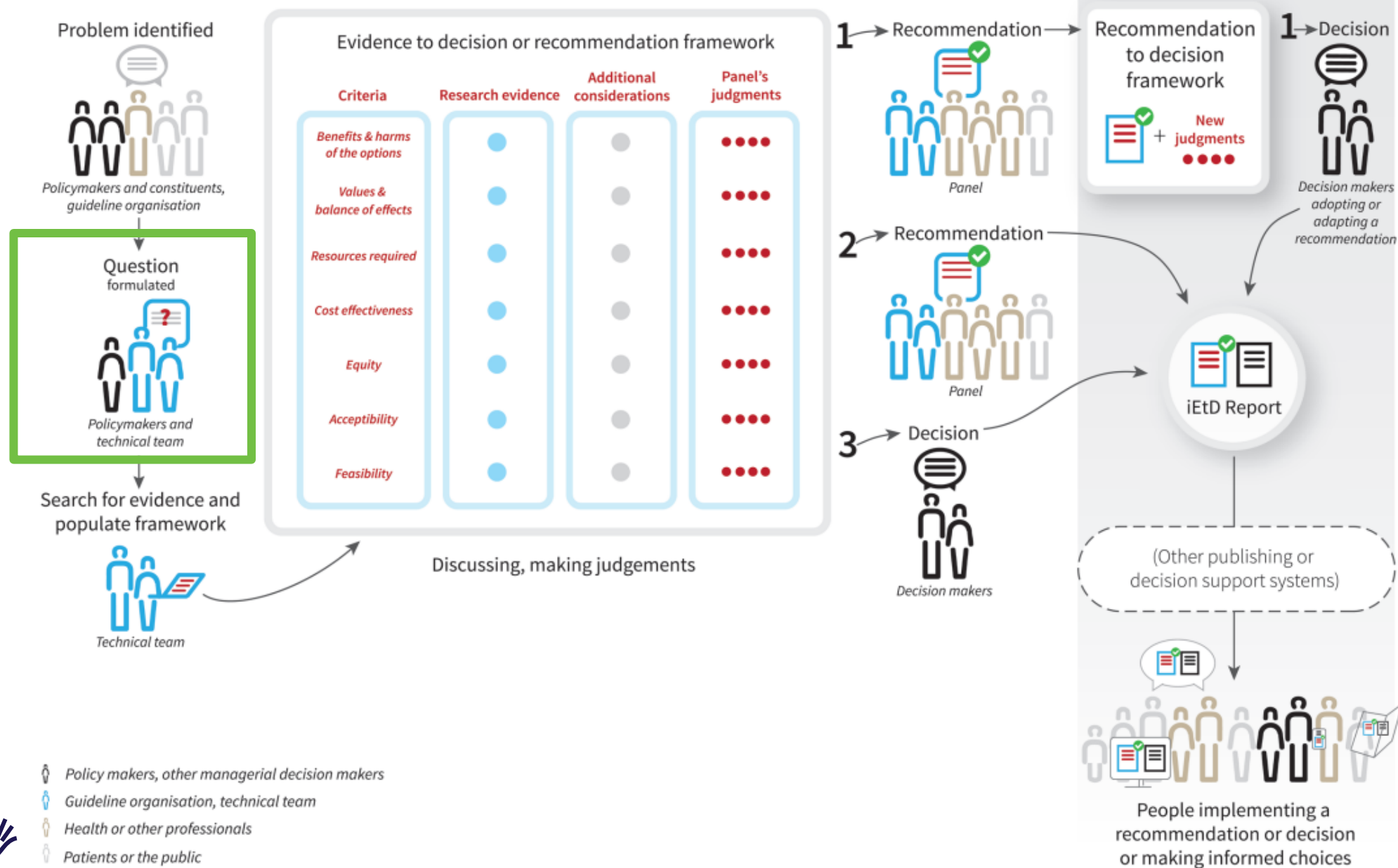
Preparing and using frameworks for producing recommendations or decisions

Using the output



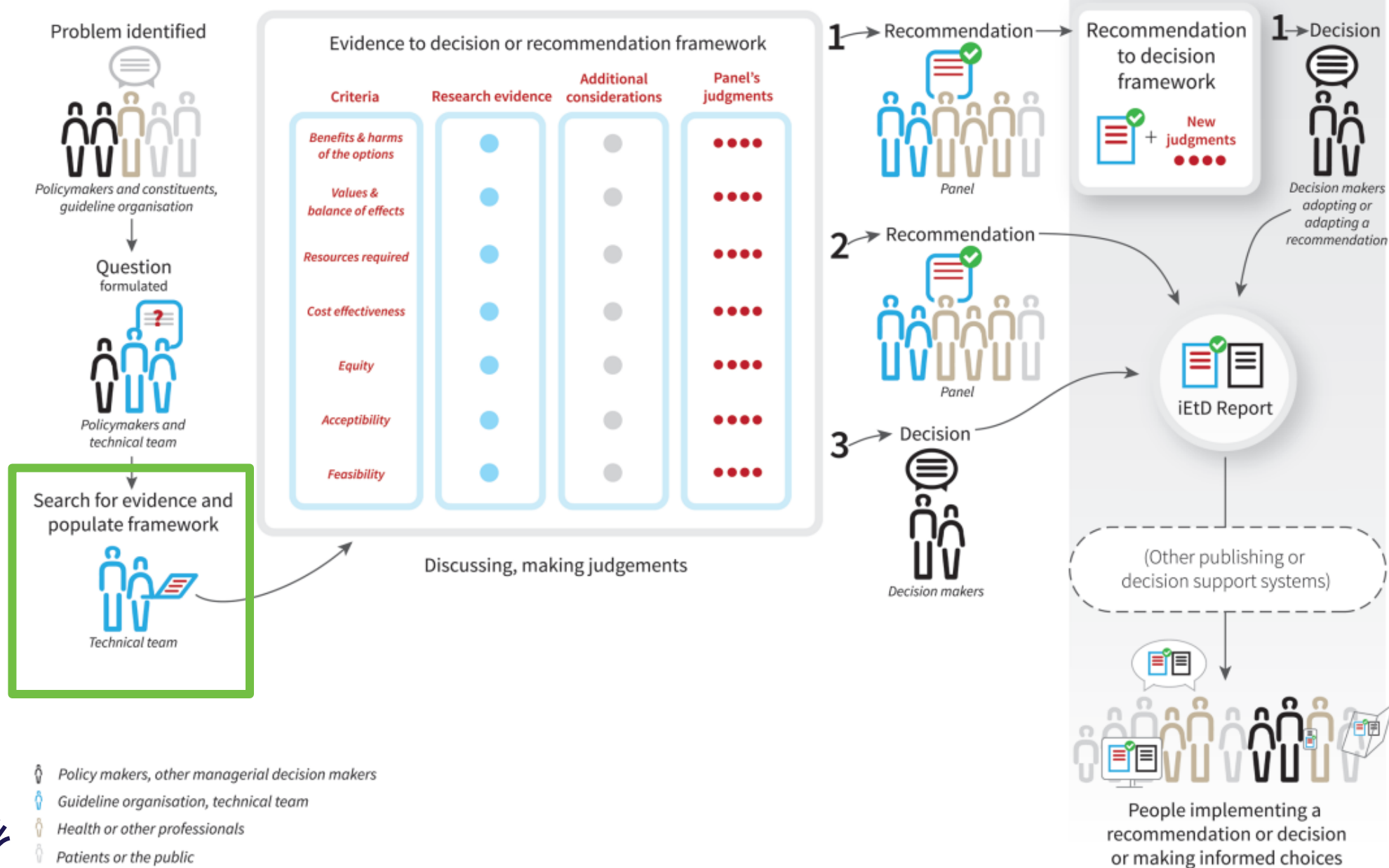
Preparing and using frameworks for producing recommendations or decisions

Using the output



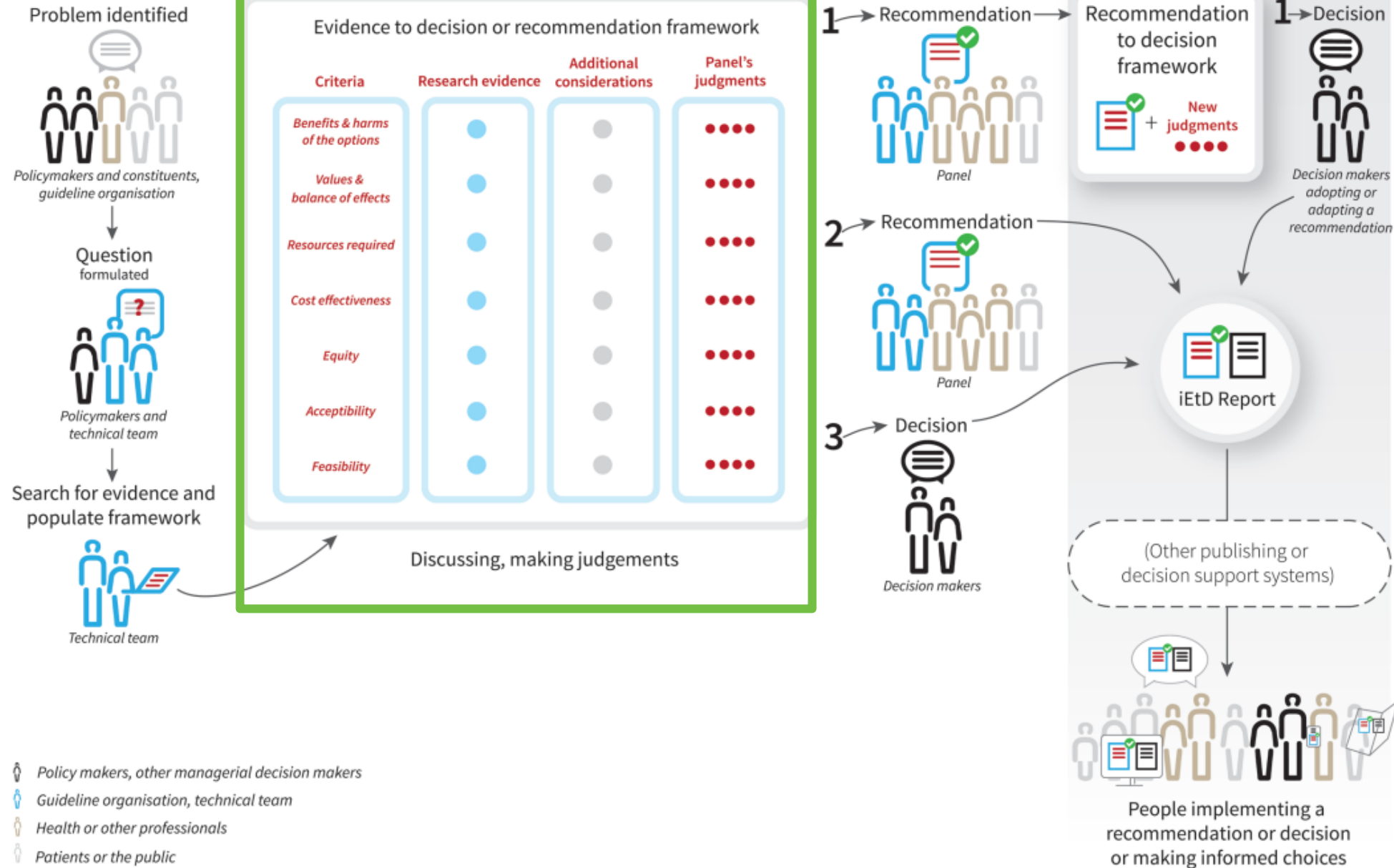
Preparing and using frameworks for producing recommendations or decisions

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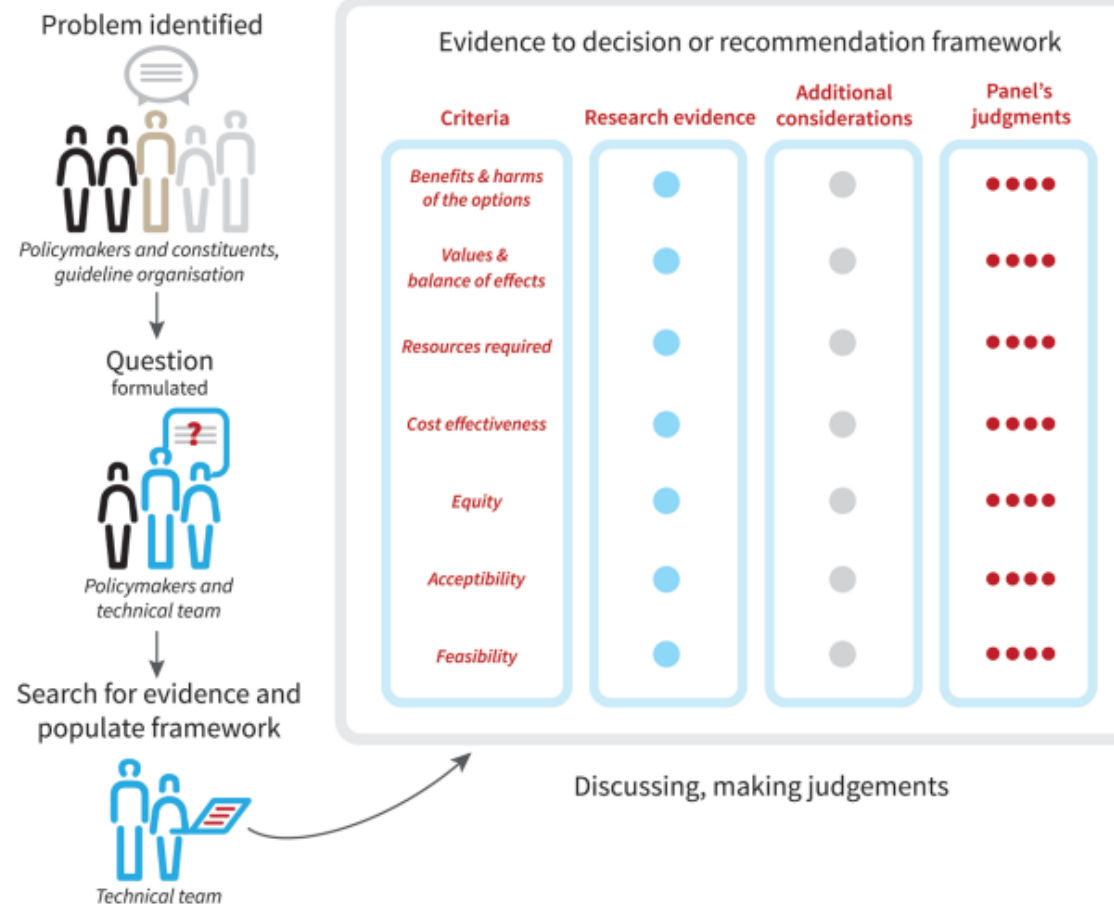


Preparing and using frameworks for producing recommendations or decisions

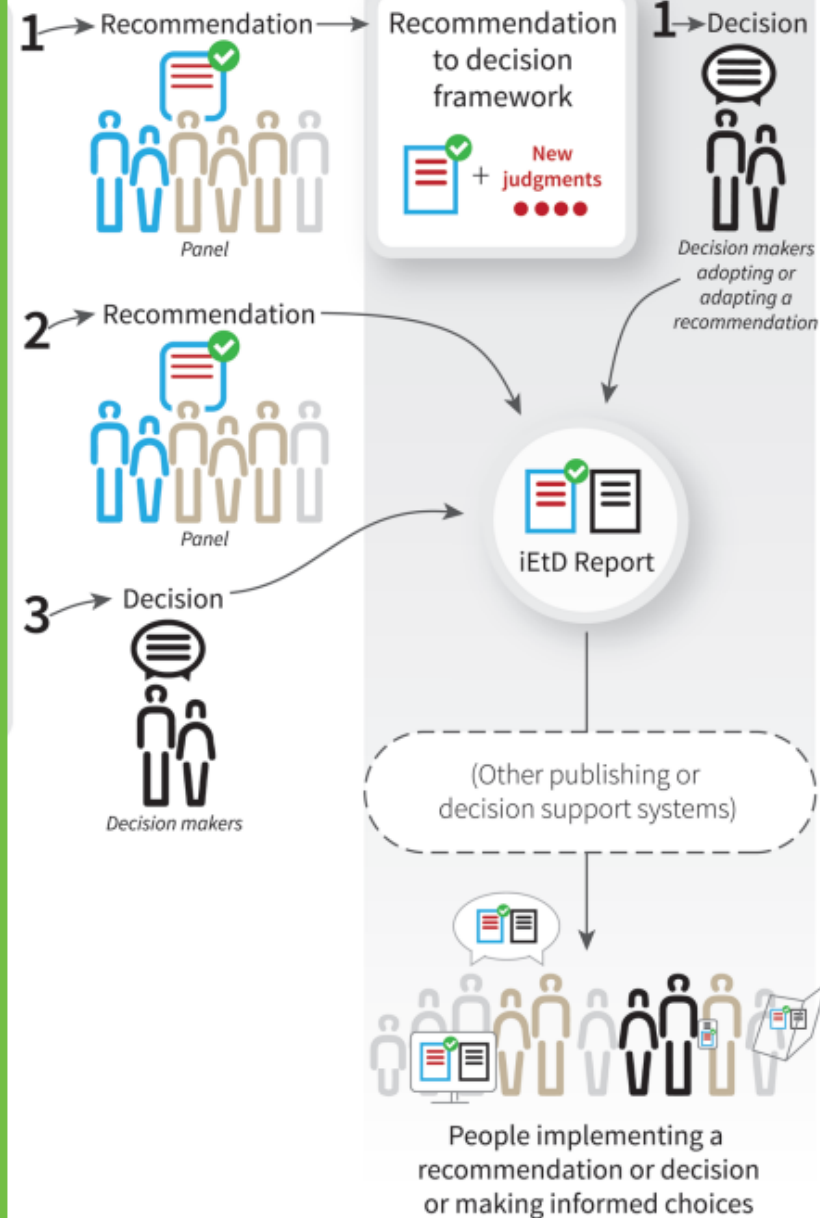
Using the output



Preparing and using frameworks for producing recommendations or decisions

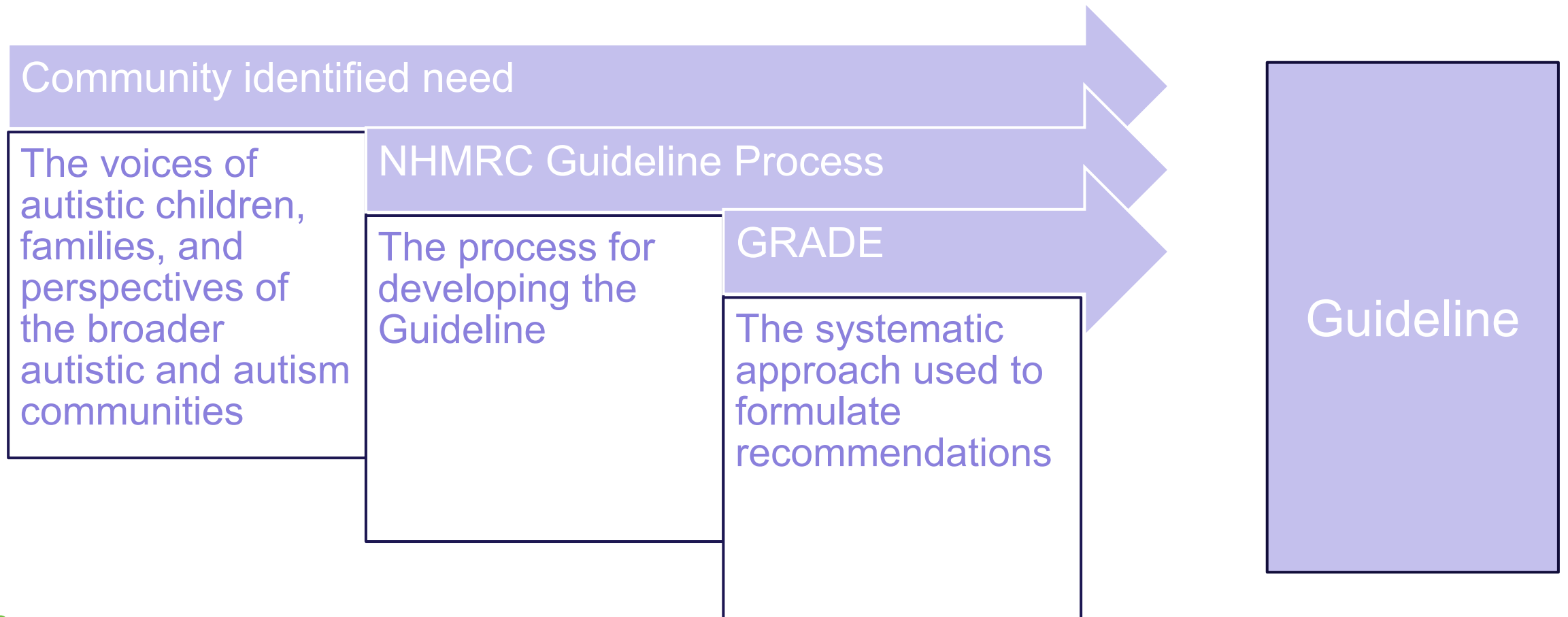


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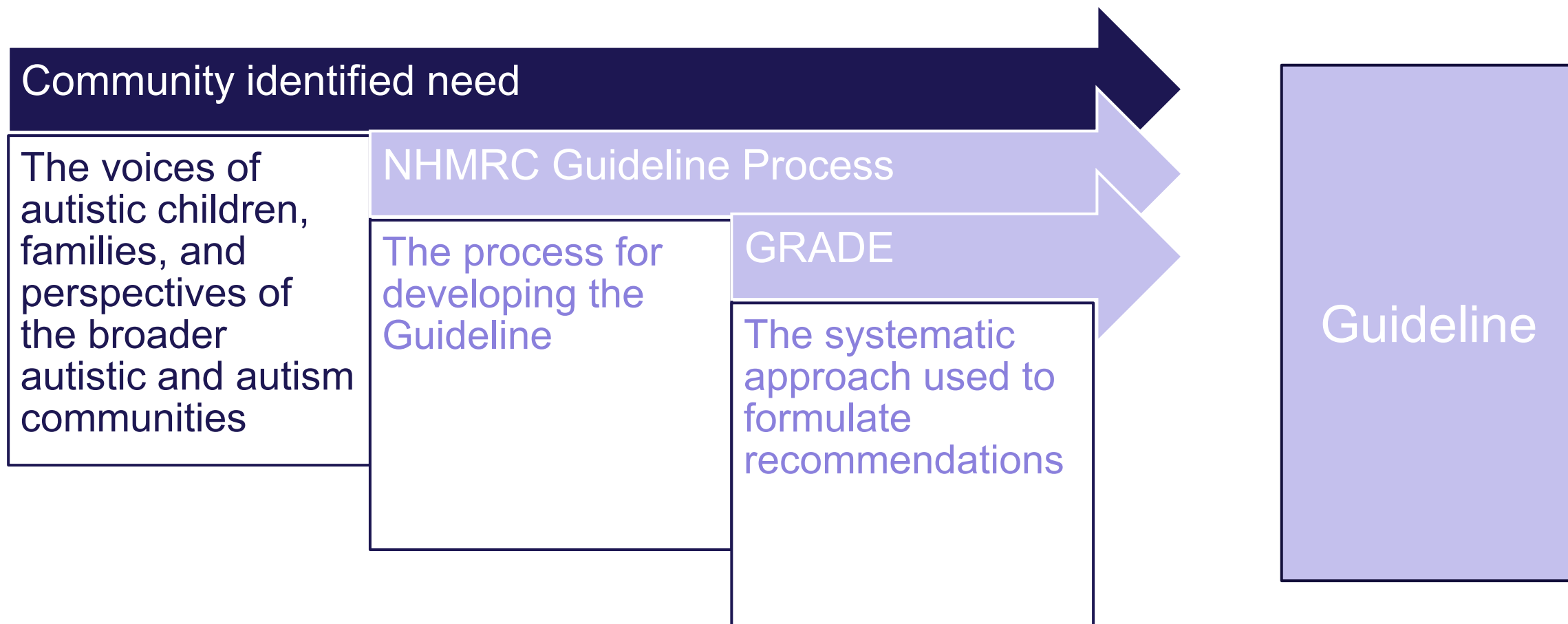


- Policy makers, other managerial decision makers
- Guideline organisation, technical team
- Health or other professionals
- Patients or the public

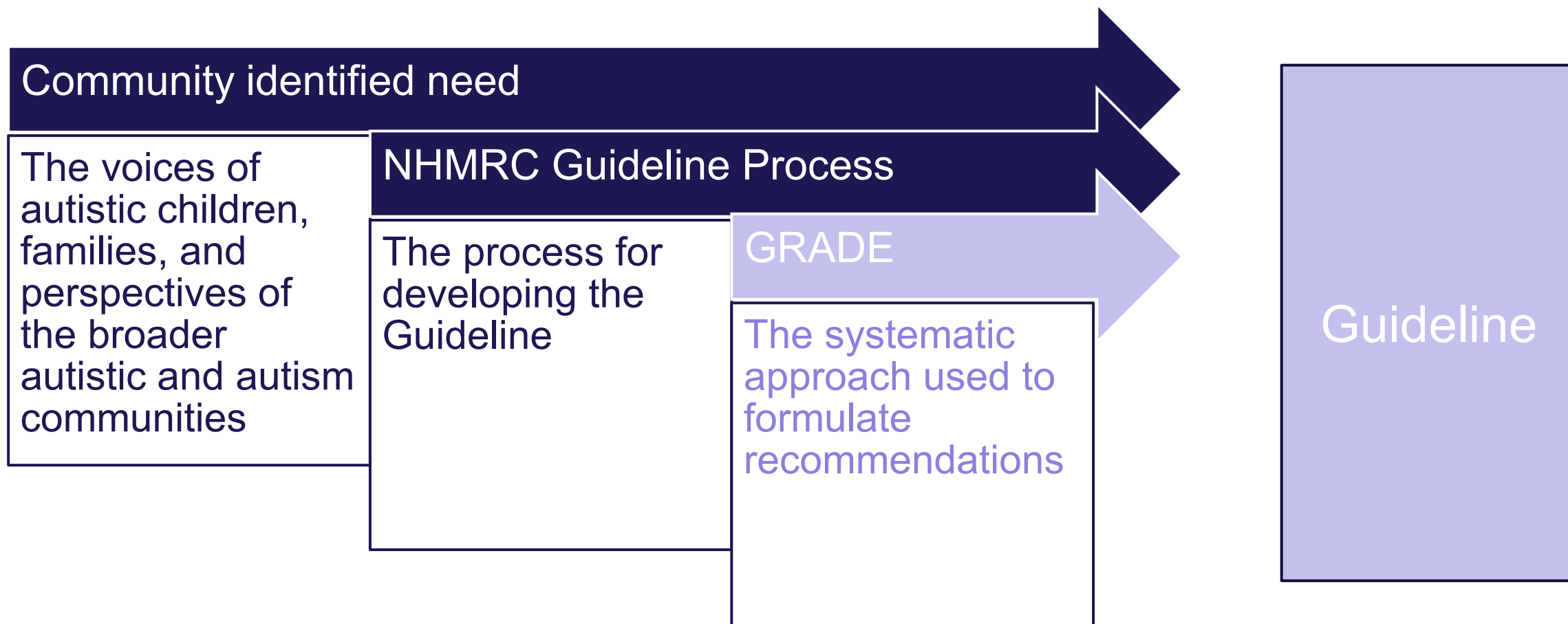
Summary so far...



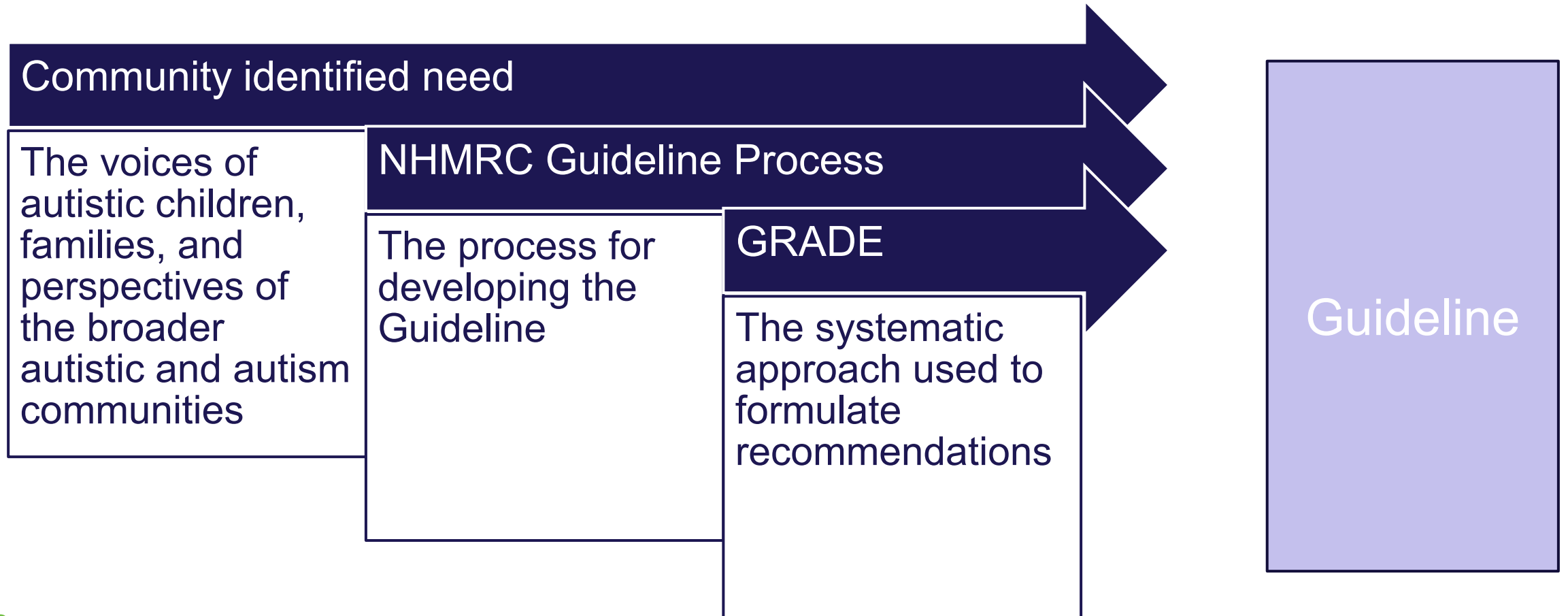
Summary so far...



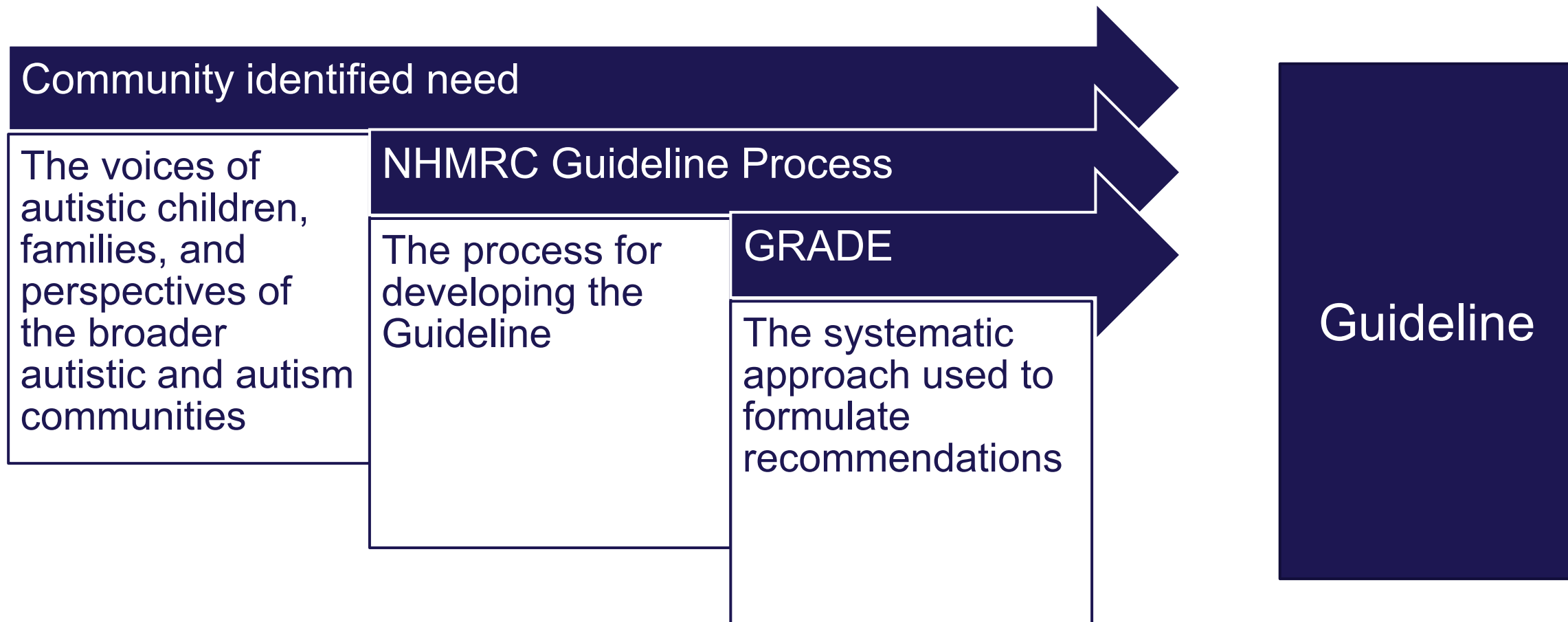
Summary so far...



Summary so far...



Summary so far...



From questions, to evidence, to Recommendations

Step 1: Establish the Guideline Development Group (GDG)

Step 2: Define Guideline questions

Step 3: Gather evidence

Step 4: Move from evidence to recommendations

Step 5: Public consultation on Draft Guideline

Step 6: Revise and release Guideline

Step 1: Establish the Guideline Development Group (GDG)

Started with perspectives,
knowledge, and skills, not people





Gary Allen is the Senior Policy Officer Human Research Ethics and Research Integrity at Griffith University. Gary has worked in the human research ethics area since 1997, working with a number of research institutions, state and federal departments, private companies and research ethics committees internationally. He also has a degree in education and a professional doctorate in social sciences. Gary brings extensive experience in regards to the national and international governance of ethical conduct in research.



Mx Katharine Annear is a founding member of the Autistic Self Advocacy Network of Australia and New Zealand, a registered Developmental Educator, and Casual Academic at Flinders University. They bring lived experience as an Autistic person who also has numerous Autistic family members, and are a passionate advocate for co-design in research and public policy and the translation of research and policy into meaningful practice for disabled people.



Professor Valsa Eapen is the Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales. An internationally-recognised child psychiatrist and researcher, Valsa's expertise combines extensive experience in childhood mental health and developmental disorders from a clinical and basic science research perspective.



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Jess Feary is the Victoria and Tasmania Coordinator for Positive Partnerships. She has a background in occupational therapy and public health and brings over 15 years' experience working with neurodiverse people and their families in clinical, research, policy and educational settings.



Dr Emma Goodall is an autistic author, advocate, qualified meditation and mindfulness teacher and adjunct research fellow at the University of Southern Queensland. She is the Manager for Content & Research for Positive Partnerships and also runs Healthy Possibilities, a consultancy offering personal life coaching alongside autism specific continuing professional development for educators and families and NDIS services (many with a link to interoception). Emma speaks widely on the topic of interoception and the role mindful body awareness plays in emotional regulation.



Teresa Pilbeam is a special education teacher, an advocate for informal family carers, and has worked alongside First Nations peoples across Australia. Teresa has 30 years' experience in special education, contributed to carer and disability reform for over 10 years, is an Independent Director on government and profit-for-purpose state and federal councils and boards, and has a lived experience of autism spectrum and complex disability. Teresa brings experience and expertise of governance, ways of working with Aboriginal and Torres Strait Islander peoples, and an enthusiasm for enabling the voice of informal family carers to be heard in cross-sector conversations.



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Felicity Rose is a Project Manager at Telethon Kids Institute. Her current project is to further implement the National Guideline for the Assessment and Diagnosis of Autism into clinical practice. She has a professional background in science and research and is also the parent of a young person on the autism spectrum.



Sarah Pillar is the Integration Project Manager at CliniKids, Telethon Kids Institute. She has a professional background in Speech Pathology and brings experience in providing clinical services to children on the autism spectrum and their families. Sarah is a PhD candidate through the University of Western Australia.



Dr Nancy Sadka is a Research Fellow at the Olga Tennison Autism Research Centre, La Trobe University. She works in the early identification and diagnosis of autism and is an advocate for families and children on the spectrum over the life span. She also is the mother of two children on the autism spectrum and brings to the GDG over 25 years of lived experience.



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Dr Natalie Silove is a Clinical Associate Professor in the Discipline of Paediatrics and Child Health, University of Sydney and Senior Lecturer (Conjoint) at the School of Psychiatry (UNSW). She is also the Head of Child Development Services; Senior Staff Specialist, Child Development Unit at The Children's Hospital Westmead. She brings over 30 year's experience working with children and young adults with special needs, their families and schools.



Dr Rhylee Sulek is a Research Fellow within the School of Health Sciences and Social Work, Griffith University. She brings experience in working with young children on the autism spectrum and their families when receiving early supports and therapies, and the inclusion of key stakeholders in the co-production of research.



David Trembath is an Associate Professor in Speech Pathology at the Menzies Health Institute Queensland, Griffith University. He brings to the GDG over 20 years of clinical-research experience working with children on the autism spectrum and their families.



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Dr Kandice Varcin is a Research Fellow at the Menzies Health Institute Queensland, Griffith University. She is also a registered psychologist who brings experience and expertise in research focused on early development and the evaluation of therapies and supports for young children and their families on the autism spectrum.



Dr Hannah Waddington is a senior lecturer at Victoria University of Wellington and the Clinic Lead of the Victoria University of Wellington Autism clinic. She is also a practicing educational psychologist who brings experience in provision of early support to children on the autism spectrum and their families.

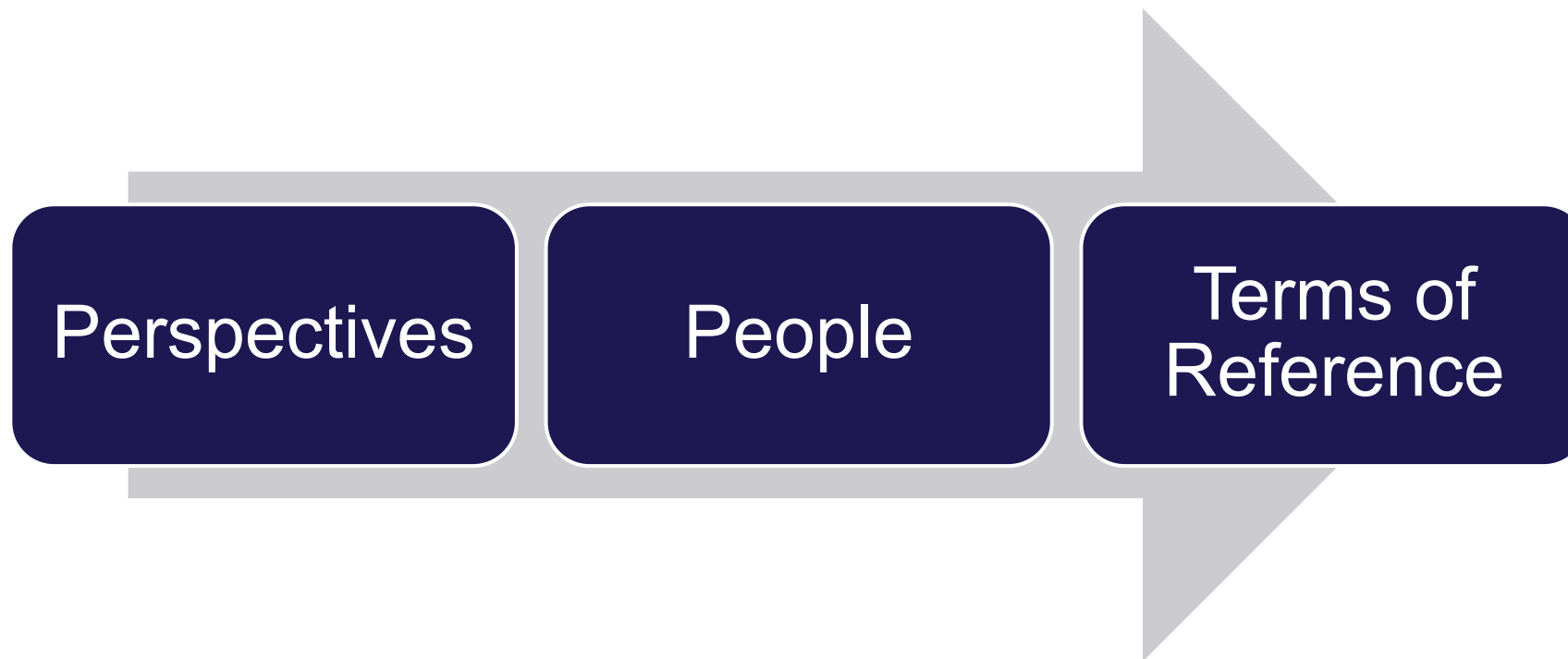


Andrew Whitehouse is Angela Wright Bennett Professor of Autism at the Telethon Kids Institute and the University of Western Australia. He is the Director of CliniKids, a clinical research centre of excellence for children on the autism spectrum. Andrew is also Autism CRC's Research Strategy Director, and he chaired the development of the National Guideline for the Assessment and Diagnosis of Autism in Australia.



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Summary of Process for appointing GDG



Forming a Reference Group

Forming a Reference Group



Stakeholder group	National peak body	Representative	Position
Autistic people	Autistic Self Advocacy Network – Australia and New Zealand	Lisa Smith	Member
Family members of autistic people	Autism Awareness Australia	Nicole Rogerson	Chief Executive Officer
First Nations peoples	First Peoples Disability Network Australia	Jess Styles	Director, Programs
Culturally and linguistically diverse communities	Federation of Ethnic Communities’ Council of Australia	Daniel Coase	Senior Advisor
Focusing on children’s health	Neurodevelopmental and Behavioural Paediatrics Society of Australasia	Ashanthi Munasinghe	Member
Focusing on children’s social-communication development	Speech Pathology Australia	Amy Fitzpatrick	Senior Advisor - Disability
Focusing on children’s physical development	Australian Physiotherapy Association	Nicole Haynes	Member
Focusing on children’s cognitive development and mental health	Australian Psychological Society	Tamara Cavenett	President

Stakeholder group	National peak body	Representative	Position
Focusing on children’s sensory development and occupations	Occupational Therapy Australia	Karen Brown	Division Manager (ACT, NSW)
Representing service providers (peak body)	Australian Autism Alliance	Frances Scodellaro	Member
Representing services (early childhood)	Relmagine Australia (formerly Early Childhood Intervention Australia)	Trish Hanna	Board Chair
Representing services (education)	Australian Association of Special Education	Patrick Kelly	President
Representing services (rural health)	National Rural Health Alliance	Gabrielle O’Kane	Chief Executive Officer
Representing researchers	Australasian Society for Autism Research	Jessica Paynter	Vice President
Representing policy advisors	Autism Advisory Group to the National disability Insurance Agency	Jim Mullan	Member
Government	National Disability Insurance Agency	Sam Bennett	General Manager Policy, Advice and Research

Reference Group Roles

Activity	In Scope
Input into Guideline questions	No
Research Reviews	No
Community consultation	Feedback on activities and inviting members to contribute
Formulating Recommendations	No
Feedback on Draft Guideline	As part of Public Consultation (Reference Group meeting and written submissions)
Refining Guideline	No
Dissemination and Implementation	Will make independent decisions regarding sharing, endorsing, and/or implementing the Guideline

Step 2: Define Guideline questions

Context	Question
Overarching principles	What guiding principles should be followed when providing supports to children on the autism spectrum and their families?
Goal setting	What are appropriate goals for children and families?
	How should goals be selected?
Selection and planning	What types of supports might be relevant to children and families?
	How should these supports be selected?
	What skills and knowledge are required to plan supports?
Delivery	Who should deliver supports?
	In what settings should supports be delivered?
	In what formats/modes should supports be delivered?
	In what amount should supports be delivered?
	What are the critical service interfaces for children and families?
Outcomes, quality, and safeguards	How should the effects of supports be monitored?
	How can the risk of adverse effects be reduced?
	How should adverse effects be managed?
	How should the rights of children and families be protected?



Step 3: Gather Evidence

Research Activities



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Research Activities

Activity	Studies / Participation	Examples of Information Gathered
Systematic review of existing Guidelines	14 guidelines included in review	2,298 references (i.e., quotes from guidelines) coded across 14 guidelines
Umbrella review of non-pharmacological supports	48 systematic reviews included in review	Child and family outcomes from over 38,000 participants synthesised
Systematic review of individual and family experiences	12 studies included in review	110 references (i.e., quotes from reviews) coded across 12 studies
Community Consultation		
Online community survey	667 participants provided informed consent.	7,708 qualitative quotes analysed
Focus groups	48 people participated in the focus groups.	826 qualitative quotes analysed
Brief online survey	46 people participated in the brief online survey.	69 qualitative quotes analysed
Parent reflections	25 people participated in the reflection activity.	70 qualitative quotes analysed
Expression through artwork	The Guideline Development Group did not receive any submissions for this activity.	The Guideline Development Group did not receive any submissions for this activity.
Delphi survey	72 practitioners completed the first round 59 practitioners completed the second round	214 statements with consensus agreement

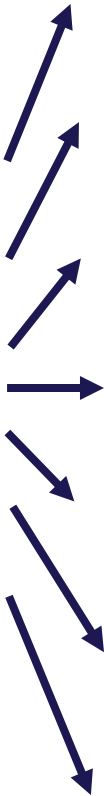
Evidence from many voices, many perspectives

Sources of evidence (i.e., research activities)	Populations represented by each evidence source						
	Autistic children	Autistic young people	Autistic adults	Parents	Family members	Practitioners	Other community members
Systematic review of existing guidelines							
Systematic review of intervention effects							
Systematic reviews of child and family experiences							
Online community survey							
Focus groups							
Delphi surveys							
Brief online survey							
Parent reflection							
Expression through art							

Step 4: Moving from evidence to recommendations

Evidence summaries

Sources of evidence (i.e., research activities)	Populations represented by each evidence source						
	Autistic children	Autistic young people	Autistic adults	Parents	Family members	Practitioners	Other community members
Systematic review of existing guidelines							
Systematic review of intervention effects							
Systematic reviews of child and family experiences							
Online community survey		Reflecting on childhood	Reflecting on childhood				
Focus groups			Reflecting on childhood				
Delphi surveys			Reflecting on childhood				
Brief online survey		Reflecting on childhood	Reflecting on childhood				
Parent reflection		Reflecting on childhood	Reflecting on childhood				
Expression through art		Reflecting on childhood	Reflecting on childhood				



Evidence Source		Evidence
Systematic Reviews	Child and family experiences	
	Umbrella Review	
Community Consultation	Delphi	
	Agreement	
	Qualitative	
Community Consultation	Survey – Quantitative	
	Autistic people	
	Parents	
	Family	
	Service Providers	
	Organisations	
	Other	
Community Consultation	Survey - Qualitative	
	Autistic people	
	Parents	
	Family	
	Service Providers	
	Organisations	
	Other	
Community Consultation	Focus Groups	
	Autistic adults	
	Parents	
Community Consultation	Brief survey	
	Reflection	

Evidence summaries

Evidence Source		Evidence
Systematic Reviews	Child and family experiences	
	Umbrella Review	
Community Consultation	Delphi	
	Agreement	
	Qualitative	
Community Consultation	Survey – Quantitative	
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	Parents	
	Family	
	Service Providers	
	Organisations	
	Other	
Community Consultation	Survey - Qualitative	
	Autistic people	
	Parents	
	Family	
	Service Providers	
	Organisations	
	Other	
Community Consultation	Focus Groups	
	Autistic adults	
	Parents	
Community Consultation	Brief survey	
	Reflection	

Recommendations and Good Practice Points

The Guideline is structured into a set of 84 Consensus-Based Recommendations with associated good practice points:

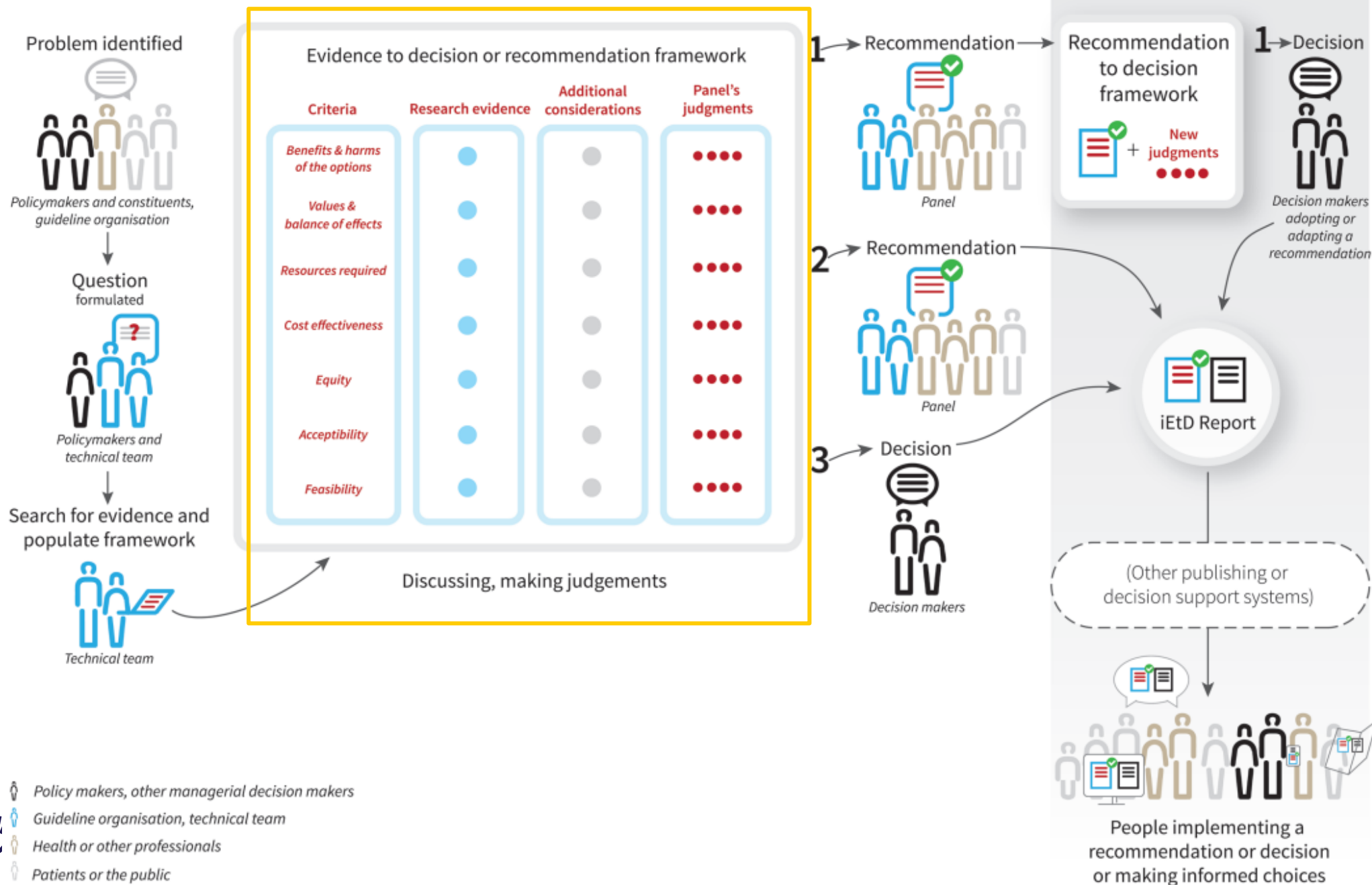
- **Consensus-Based Recommendations** are key elements of practice that must be followed for a practitioner to deliver evidence-based supports.
- **Good Practice Points** are linked to specific Recommendations, and are elements of practice that provide critical context to that Recommendation, such as how a Recommendation should be operationalised in clinical practice, or how it is applied to a specific population or under specific circumstances.

Iterative Process



Preparing and using frameworks for producing recommendations or decisions

Using the output



Evidence to Decision Judgements

Criteria	Question	Considerations	Judgements
Certainty of Evidence	What is the overall certainty of the evidence that this Recommendation is relevant?	Research evidence + Other Considerations	High Moderate Low Very low
Benefits and Harms	Are there likely to be benefits for autistic children and their families of implementing this Recommendation?		Yes Probably Yes Uncertain Probably No
	Are there likely to be risks for autistic children and their families of implementing this Recommendation?		Yes Probably Yes Uncertain Probably No
	Are the benefits for autistic children and their families likely to outweigh any risks?		Yes Probably Yes Uncertain Probably No
Values and Preferences	Is the Recommendation consistent with the values and preferences of autistic children and their families?		Yes Probably Yes Uncertain Probably No
Resources	Is the Recommendation likely to require additional resources from children and families?		Yes Probably Yes Uncertain Probably No
	Is the Recommendation likely to require additional resources from practitioners?		Yes Probably Yes Uncertain Probably No
Equity	What would be the impact on health equity?		Increased Probably Increased Uncertain Probably Reduced Reduced
Acceptability	Is the Recommendation likely to be acceptable to children and families?		Yes Probably Yes Uncertain Probably No
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Strength of Recommendations

Determined by the GDG, according to GRADE:

- **Strong Recommendations:** Reflect a high degree of confidence in relation to all EtD judgements
- **Conditional Recommendations:** Indicate uncertainty in relation to one or more EtD judgements

Strength of recommendations help readers consider *how* to implement recommendations, not which ones to implement or prioritise.

Summary



Step 5: Public Consultation on Draft Guideline

Step 6: Revise and release Guideline

How do you provide feedback?



Public Consultation

Purpose:

- To share the Guideline and supporting documents
- Listen to the feedback and revise the Guideline

When:

- July 18 to August 29, 2022

Public Consultation

How?

- Via Autism CRC website
- Either as an individual or and organisation

On the Autism CRC webpage you will see:

Draft

Guideline

Draft

Summary of
Evidence

Draft

Easy English
Summary of
Principles

Draft

Administration
and Technical
Report

On the Autism CRC webpage you will see:



Public Consultation Feedback Survey



AutismCRC



You can choose to:

- Complete this as an individual (completely online)
- Complete this as an organisation (download form, then upload)





You will have the option (one or both):

- Provide comments about **sections** of the Guideline (e.g., goal setting)
- Provide feedback about **one or more Recommendations**





We want to ensure the process is as equitable as possible:

- 6 week time period exceeds requirements
- Accessibility functions enabled within REDCap
- Word limits for each section
- We will not undertake to look at links/references



The process will be comprehensive and transparent:

- Every comment will be read by multiple members of the GDG
- The response to each comment will be reviewed by multiple members of the GDG
- Every comment and decision will be documented by the GDG





What happens to the information?

- The GDG will read and respond to every comment
- The GDG will forward all de-identified responses to NHMRC (Required so that they can review our Public Consultation process)
- All feedback from organisations (and brief GDG responses) will be published with the Guideline
- Individuals who provide feedback can choose whether their de-identified feedback is published with the Guideline

What happens next?



July

August

September

October →

Public Consultation

GDG Review Feedback

GDG Revise Guideline

Guideline Published

Dissemination

Implementation



AutismCRC

Thank you

This presentation presents the process so many of you have contributed to, and we hope will continue to do so

We warmly welcome questions