

Queensland Clinical Guidelines

Translating evidence into best clinical practice

Maternity and Neonatal

Consumer engagement strategy



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Cultural acknowledgement

We acknowledge the Traditional Custodians of the land on which we work and pay our respect to the Aboriginal and Torres Strait Islander elders past, present and emerging.

Document control

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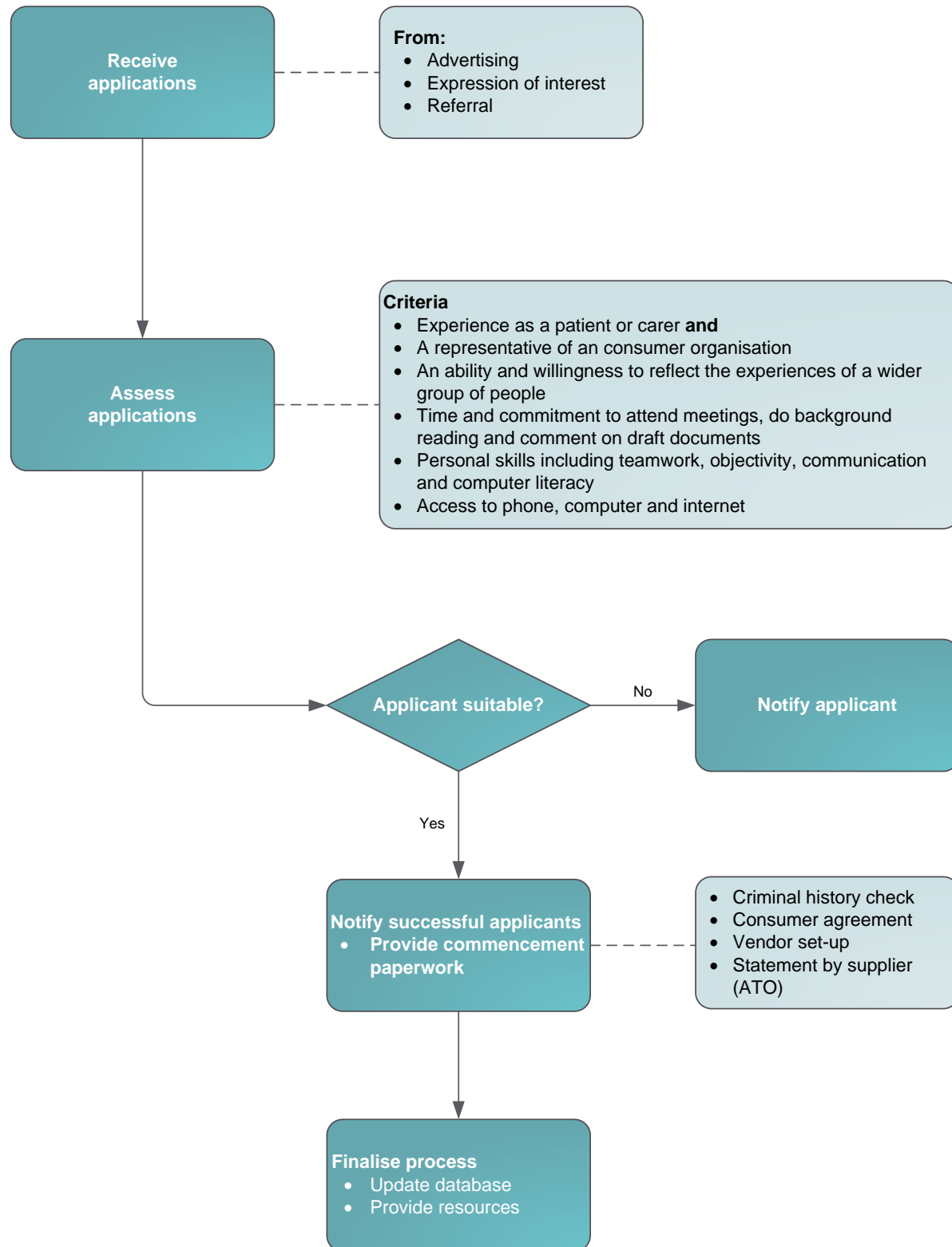
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Flow Summary: Consumer recruitment and selection



ATO Australian Taxation Office

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Abbreviations

QCG	Queensland Clinical Guidelines
HCQ	Health Consumers Queensland
NSQHS	National Safety and Quality Healthcare Standards
ACSQHC	Australian Council for Safety and Quality in Health Care

Definitions

Collaboration	Work together; join forces; act as a team.
Consultation	Discussion aimed at collecting information, ascertaining opinions or reaching an agreement; meeting with an expert in the field. ¹
Consumer	A person who uses, or potentially uses health services, including their family and carers whose participation may be as an individual, consumer representative or organisation of consumers. ²
Formal engagement	There is a role description/statement which articulates the roles and responsibilities for which a consumer, carer or community member is to be assigned. Expressions of interest are promoted widely. There is a transparent recruitment and selection process for appointment to the role.
Informal engagement	Consumers, carers and community members who provide input into aspects of service planning, delivery or evaluation for which there is no role statement or selection and recruitment process.
Payment of engagement fees	Payment offered for participation in engagement activities.
Reimbursement	Repayment for money already spent, e.g. fuel, parking.
Representative	Spokesperson, delegate...of an organisation A consumer representative is a committee member who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers. ³
Representing	Act or speak for another, act for another officially as advocates or consultants. ³

1 Purpose

The purpose of this document is to communicate the Queensland Clinical Guidelines (QCG) strategy for engaging consumers in development and review of statewide clinical guidelines and associated resources.

1.1 Background

QCG was established in August 2008 with the mission of translating evidence into best clinical practice. Consumers from a range of organisations, have been valuable in supporting this mission by participating in the QCG steering committee and guideline development working parties. Participation up to 2015 was only recognised with a formal thank you letter.

In Queensland there has been greater support and recognition of the importance of partnerships between consumers and clinicians. Since 2015 QCG has integrated this important aspect of care into statewide clinical guidelines by strengthening and formalising engagement with consumers in alignment with accepted best practice. This includes:

- Developing a consumer engagement strategy
- Establishing a network of consumer contacts
- Formalising the recruitment and selection of consumer representatives
- Remunerating consumer participation.

Increased involvement of consumer representatives in development and implementation of clinical guidelines enables better partnerships between clinicians and consumers, and better personalised care.

1.2 Strategic alignment

The valuable and important contribution consumers make to health service planning and delivery is well recognised and accepted both nationally and internationally.^{1,2,4-6} The importance of consumer engagement is acknowledged within a variety of strategic documents guiding health services in Queensland including:

- Australian Commission on Safety and Quality in Health Care National Safety & Quality Standards in Health Care Standard 2 Partnering with Consumers⁷
- Code of Conduct for Queensland Public Servants⁸
- National Code of Conduct for Health Care Workers (Queensland)⁹
- Australian Commission on Safety and Quality in Health Care Australian Charter of Healthcare Rights: My healthcare rights¹⁰
- Department of Health Strategic Plan 2019-2023¹¹
- Metro North Hospital and Health Service (MNHHS) *Partnering with consumers—reimbursement and payment procedure* Version 2.0 (Procedure 004369)¹²

1.3 Consumer engagement

There are strong and validated reasons and benefits associated with consumer involvement in guideline development, implementation and review.^{2,4}

These include:

- Improving relationships between health care providers and the community
- Improving partnership between patient and clinician by ensuring that the wording and presentation of guidelines are respectful, and the recommendations promote compliance by clinical staff
- Enhancing legitimacy and support of the development process, and for receptivity to final guideline uptake and dissemination
- Enhancing creative effort, novel external perspectives and challenges, and adding relevance and appropriateness
- Appropriately accounting for issues that are important to patients and the public
- Potentially improving health outcomes for consumers
- Supplementing gaps in the evidence, or obtaining a wider source of patient/public experiences and views
- Supporting sustainable community interaction and capacity
- Enhancing acceptance and uptake of guidelines in the local context
- Supporting representation of specific groups within the patient population, such as those who are unrepresented or 'seldom heard'
- Supporting responsible decision making based on public needs and priorities
- Adding value to problem solving issues that arise from the expertise and energy of the experiences of individuals and communities
- Reducing political risk as public confidence is increased with legitimacy and credibility of decisions

2 Methods of consumer engagement

Three major strategies have been described to engage consumers. A mixed approach is possible that includes consultation (while limiting the number of consumers to a manageable and viable size) as well as participation and communication (either directly or through consumer groups).^{4,13,14}

Table 1. Strengths and weaknesses of consumer involvement strategies

Strategy	Strengths	Weaknesses
Consultation	<ul style="list-style-type: none"> • Gathers views of large number of Individuals • Methods add to evidence base • Helps public accept guideline recommendations • Identifies topics important for public • Useful in early stages of development • May be undertaken online 	<ul style="list-style-type: none"> • Tends to seek out individual viewpoints
Participation	<ul style="list-style-type: none"> • Fosters deliberation and mutual learning • Enables consumers to be present during deliberations • Fosters mutual influence between consumers and professionals • Fosters collective perspective • Supports compromise or consensus 	<ul style="list-style-type: none"> • Allows involvement of small number of people • May miss perspective of vulnerable groups
Communication	<ul style="list-style-type: none"> • Useful in dissemination and implementation • Increases public knowledge and awareness of recommendations which may increase uptake 	<ul style="list-style-type: none"> • Decision aids may be required to assist consumers weigh up pros and cons for 'grey areas'

2.1 Consumer information

Consumer information meets pre-determined criteria including (but not limited to) options with benefits and risks, patient centred outcomes, understanding, and accessibility. This:

- Ensures consumer information is understood by consumers
- Supports guideline implementation and improves health care
- Helps consumers make informed decisions that are based on best available evidence
- Helps consumers learn about the current standard of care and how their condition is best treated or managed
- Supports the relationship between consumers and clinicians, as decisions are based on the same body of evidence and standards of care^{4,6,14}

3 Barriers and opportunities

Proceeding with a formal process for consumer engagement with appropriate remuneration carries little risk and significant opportunity for benefit. However, a number of challenges have been identified and these along with potential mitigation strategies are outlined in Table 2. Risk Matrix

Table 2. Risk Matrix

Decision option	Negative consequence if action occurs	Risk rating
Proceed with formal consumer strategy ¹⁵	<ul style="list-style-type: none"> • Less than 2% delay to administrative, workflow or corporate programs—negligible impact on achieving objectives • Cost of remuneration must be incorporated into QCG budget • Resources (human, time and money) must be assigned to manage and support strategy 	Low/likely
Do not proceed with formal consumer strategy ¹⁵	<ul style="list-style-type: none"> • No harm (e.g. a preventable clinical incident classified as SAC3) • Complaints and/or negative local media attention • Potential for damage to Queensland Health reputation • Quality of QCG guidelines and associated resources diminished 	Medium/unlikely

3.1 Challenges and mitigation strategies

Formal consumer engagement poses a low level of organisational and operational risk. Mitigation strategies further reduce these risks.

Table 3. Potential challenges and mitigation strategies

Challenge ^{1,3,4,11,14}	Mitigation
High level of scientific, medical and technical information	<ul style="list-style-type: none"> • Provide some training as part of induction • Provide support person to guide and assist, but not influence
Role perceived by professionals as not value adding or by consumer as tokenistic	<ul style="list-style-type: none"> • Inform clinical lead and members of working party about consumer role • Clinical lead acts as role model • Program officer provides support • Consumer payment so that there is acknowledgement of the consumers' expertise and the value of their input
Engagement in virtual groups	<ul style="list-style-type: none"> • Link with program officer by phone and email • Induction program • Include computer literacy as a criterion in role description
Feedback from consumers may not be incorporated into guideline	<ul style="list-style-type: none"> • Follow usual processes for providing reasons for inclusion or exclusion of feedback
Expectations about confidentiality and conflict of interest	<ul style="list-style-type: none"> • Information resources made available to clarify

4 Resourcing

The life experiences of consumers are many and varied and may be reflected in their knowledge of systems, experience in change management and ability to evaluate. Their contribution and expertise therefore needs to be remunerated. Payment helps legitimise their role by valuing the skills and experience that they bring. It demonstrates their participation is valued and indicates the seriousness with which their contribution is taken. Additionally, consumers are likely to be more productive and supportive of the health service, provide a long-term commitment, and therefore ensure consistency and sustainability. Payment underpins respect for work done by the consumer and can stimulate performance and accountability.^{2,4} Potentially, remuneration broadens the pool of representatives.¹⁶

Importantly remuneration and reimbursement puts the consumer representative on an equal footing with others in the group and makes consumer opinion as equally valuable. This mitigates the risk of a 'them and us' issue developing.

Apart from a "sitting fee", consumer representatives are not expected to be out of pocket for any expenses they incur such as travel and car parking.¹⁶ The costs (both human and financial) associated with consumer engagement is identified and built into QCG annual budget and program of work. An efficient process for payment to consumers in line with Metro North Hospital and Health Service (MNHHS) policy is in place.¹²

4.1 Remuneration

New guidelines usually undergo three rounds of consultation and guideline reviews have two. In line with MNHHS procedure¹² consumers are paid a fee for each round of guideline working party participation. The payment schedule is reflective of the heavier workload of the first round of consultation. Consumers are also remunerated for participating in other QCG activities such as steering committee meetings.

4.2 Consumer support

Consumers require support for their participation in working parties.^{1,2,16} QCG endeavours to provide the necessary supports to consumers to enhance their participation. This includes an awareness of the need for:

- Consideration of the impact of geographical location/distance
- Language interpreters when required
- Out of session contact to answer questions or discuss matters relating to the QCG work
- Physical accessibility of meeting venues for people with disabilities
- Support workers for people with disabilities
- Cultural considerations
- Planning to address potential barriers to engagement including:
 - Ensuring consumer representatives are fully engaged with the group
 - Addressing the group if contributions by consumer representatives are not acknowledged appropriately
 - Welcoming and encouraging contributions from consumer representatives
 - Provision of orientation and induction training
 - Timely receipt of papers, minutes, and other reading material
 - Sufficient notice of meetings and other deadlines
 - Printing and hard copy forwarding of large documents if requested
 - Information and explanation of technical terms and acronyms in use

5 Recruitment and selection

A sustainable recruitment process that is equitable, transparent, accountable and efficient is required to ensure appropriate representation. Consumers endorsed by a relevant consumer organisation or group are accepted as consumer representatives.

5.1 Attributes of the consumer representative

Consumer representatives are expected to¹⁶:

- Express opinions and contribute their own experiences and those of their family members or as a member of the public
- Represent a relevant consumer organisation, and liaise with members regarding QCG matters
- Share what they consider being the common perspectives of members of their organisation, population group and networks
- Think laterally and strategically and have a clear understanding of the health system
- Contribute to decision-making
- Be able to challenge assumptions of the providers and “hold their own” with senior professionals

5.2 Roles and responsibilities of the consumer representative

Consumer representatives' roles and responsibilities^{1,12} include, to:

- Raise issues and prompt the working party to consider issues from a different experience base and range of perspectives
- Assess evidence and draft recommendations alongside health professionals
- Be accountable to the nominating organisation if they are a formal representative of that organisation
- Operate within the conditions of their appointment (including any terms of reference)
- Declare any actual or perceived conflicts of interest (COI), undergo a criminal history check and disclose any previous or current employment as a lobbyist
- Adhere to confidentiality requirements, and be held accountable to the committee for maintaining confidentiality and protecting privacy and declaring conflicts of interest in line with Queensland Health policies

5.3 Experience, knowledge and skills of the consumer representative

The consumer representative will have:

- Experience as a consumer or carer of maternity and or neonatal health care, or a representative of an organisation relevant to these
- An ability and willingness to reflect the experiences of a wider group of people through consumer organisations, forums or self-help groups
- The time and commitment to attend meetings, do background reading and comment on draft documents
- Personal skills including ability to be objective, teamwork, communication and computer literacy¹

5.4 Recruitment process

The recruitment process may be by nomination or open recruitment. Open recruitment involves advertising using a role description. Nomination occurs through organisations known to QCG. Table 4. Recruitment process comparison identifies the advantages and disadvantages of both these processes.¹⁶

Consumers are added to distribution lists and mailing groups and receive notification about QCG activities including guideline working parties and steering committee participation. They may indicate their interest in being a consumer representative by an online expression of interest.

An open selection process demonstrates inclusiveness and transparency. It is usual to recruit at least two consumer representatives to each working party to add different perspectives, as well as for social support.³

Table 4. Recruitment process comparison

Process	Advantages	Disadvantages
Open	<ul style="list-style-type: none"> • Wider range of people • Transparent • Reduces potential for conflict of interest • Avoids biases 	<ul style="list-style-type: none"> • Time consuming • Needs role description to be developed • Requires administrative overhead
Nomination	<ul style="list-style-type: none"> • Quick • Known background and ability of nominee 	<ul style="list-style-type: none"> • Less transparent • Narrows pool of applicants

5.5 Selection method

Features of the selection method include:

- A clear and legitimate process (nominations or open merit)
- Providing information about the vacancy to consumer organisations' and health professionals' websites as well as other social media sites to increase reach
- Advertising timeline sufficient for organisations to reach their members
- Giving consideration to reaching socially disadvantaged groups/organisations who may not have access to the internet, minority cultures, and ethnic groups¹⁷

6 Quality measures

Quality measures will be considered during the evaluation phase as outlined in Table 5. Suggested quality and audit measures. The QCG *Consumer engagement* strategy complies with the criteria of National Safety and Quality in Healthcare Standards (NSQHS) *Standard 2 Partnering with consumers*⁷:

- Clinical governance and quality improvement systems
- Partnering with patients in their own care
- Health literacy
- Partnering with consumers in organisational design and governance

Table 5. Suggested quality and audit measures

No	Audit criteria	Target	Document Section
1	The percentage of new or reviewed guidelines that have at least two consumers actively participating in working parties	80%	5.4 Recruitment Process
2	The percentage of recruited consumers who actively engage in a working party including timeliness of feedback that is representative of their organisation	80%	1.3 Consumer engagement 2 Methods of consumer engagement

6.1 Safety and quality

Implementation of this strategy provides evidence of compliance with the National Safety and Quality Health Service Standards (NSQHS).¹⁸

Table 6. Compliance with NSQHS

NSQHS Criteria	Actions required	Evidence of compliance
NSQHS Standard 2: Partnering with Consumers		
<p>Clinical governance and quality improvement systems to support partnering with consumers Systems are designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, measurement and evaluation.</p>	<p>Integrating clinical governance 2.1 Clinicians use the safety and quality systems from the Clinical Governance Standard when: a. Implementing policies and procedures for partnering with consumers b. Managing risks associated with partnering with consumers c. Identifying training requirements for partnering with consumers Applying quality improvement systems 2.2 The health service organisation applies the quality improvement system from the Clinical Governance Standard when: a. Monitoring processes for partnering with consumers b. Implementing processes to partnership with consumers c. Reporting on partnering with consumers</p>	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> The QCG steering committee has endorsed the <i>Consumer engagement strategy</i> <input checked="" type="checkbox"/> QCG follows MNHHS policies and procedures for remuneration of consumers <input checked="" type="checkbox"/> QCG provides written information to consumers to assist with participation in working parties, steering committee and other activities
<p>Partnering with consumers in their own care Systems that are based on partnering with patients in their own care are used to support the delivery of care. Patients are partners in their own care to the extent that they choose.</p>	<p>Healthcare rights and informed consent 2.4 The health service organisation ensures that its informed consent processes comply with legislation and best practice</p>	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> QCG seeks input from consumers when developing guidelines and consumer information <input checked="" type="checkbox"/> The QCG <i>Standard care</i> guideline has relevant information about consumer rights and informed consent

Table 6. Compliance with NSQHS (continued)

NSQHS Criteria	Actions required	☑ Evidence of compliance
<p>Health literacy Health service organisations communicate with consumers in a way that supports effective partnerships.</p>	<p>Communication that supports effective partnerships 2.8 The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community 2.9 Where information for patients, carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review 2.10 The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that: a. Information is provided in a way that meets the needs of patients, carers, families and consumers b. Information provided is easy to understand and use c. The clinical needs of patients are addressed while they are in the health service organisation a. d. Information needs for ongoing care are provided on discharge</p>	<p>☑ Consumer consultation is sought and obtained during the development of QCG guidelines. Refer to the acknowledgement section of the guidelines for details ☑ Consumer information is developed to align with guidelines and includes consumer involvement during development and review ☑ Consumer information is developed using plain English and with attention to literacy and ease of reading needs of the consumer</p>
<p>Partnering with consumers in organisational design and governance Consumers are partners in the design and governance of the organisation.</p>	<p>Partnerships in healthcare governance planning, design, measurement and evaluation 2.11 The health service organisation: a. Involves consumers in partnerships in the governance of, and to design, measure and evaluate, health care b. Has processes so that the consumers involved in these partnerships reflect the diversity of consumers who use the service or, where relevant, the diversity of the local community 2.14 The health service organisation works in partnership with consumers to incorporate their views and experiences into training and education for the workforce</p>	<p>☑ Consumers are members of guideline working parties ☑ Guidelines are based on the best available evidence ☑ Guidelines and consumer information are endorsed by the QCG and Queensland Statewide Maternity and Neonatal Clinical Network Steering Committees which includes consumer membership</p>

7 Conclusion

QCG has a formal consumer engagement strategy that is resourced and implemented. The following strategies are in place:

- A mixed approach of engagement including consultation, participation and communication
- Recruitment open to any applicants that meet the requirements of the role description including membership of a consumer organisation
- A formal recruitment and selection process
- Resources and supports are developed or sourced for consumers including:
 - Role description
 - Frequently asked questions information sheet
 - Induction manual
 - Medical terminology
 - Research critiquing for the consumer
- Clear, transparent and approved process are in place for the purposes of remuneration and reimbursement
- Working parties including the clinical leads are informed with regard to constructive consumer involvement on the working parties
- Consumers are involved with the consultative phases of guideline development
- Consultation processes are in line with other working party members, that is a virtual working party communicating by email with occasional need for teleconferencing
- Consumer information is developed for each new guideline and progressively for current ones as they are reviewed and as resources allow
- Opportunities for involvement are made available to consumers in addition to guideline development as they are identified (e.g. implementation activities)

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