Feedback on the shared decision toolkit – August 2023

Invited reviewers			Type of response and declared interests
AMc	Alana McLellan	Specialist Perinatal Mental Health Midwife, NHS Lanarkshire	*Individual response* NHS Lanarkshire is currently involved in research with MAP research project- Methods of assessing perinatal anxiety work packages. I am the principle investigator for NHS Lanarkshire.
CM	Claire Mollison	Social Worker, Lanarkshire	*Individual response* Nothing declared
--		NHS Borders CMHT	*Individual response* Nothing declared
GA	Gillian Anderson	Consultant psychiatrist, NHS Forth Valley	*Individual response* Nothing declared
LM	Lynne Mosley Publish response with name, job title and place of work	CPMHT Team Lead, NHS Fife	*Individual response* Nothing declared
MCS	Marie Claire Shankland	Head of Programme Specialist Practice	*Individual response*

		Psychology, Head of Programme Specialist Practice Psychology	Nothing declared
VR	Victoria Reid	Bipolar Scotland; Oxfam Person with lived experience of bipolar disorder, mother of twins, support group facilitator with Bipolar Scotland	*Individual response* I am a representative/employee of a voluntary organisation supporting people with a condition or who use a service which relates to the topic under review. I have direct experience of the condition or the services under review (as either a service user/patient/carer of a person with a related condition). I am likely to be directly impacted by the topic under review.

Open consultation			Type of response and declared interests
--		Maternal Mental Health Alliance UK	*Organisation response* The Maternal Mental Health Alliance (MMHA) is a UK-wide charity and network of over 120 organisations, dedicated to ensuring women and families affected by perinatal mental health problems have access to high-quality, comprehensive perinatal mental health care. Draft recommendations in this SIGN guideline will have no discernible impact on the function or productivity of our organisation.
--		Trainee Health Visitor, NHS Forth Valley	*Individual response* Nothing declared
EMH	Eilidh Macdonald-Harte, Managing Coordinator, Counselling East Christina Smiley, Head of Service, Children and Families Mairi McNaughton, Managing Coordinator	CrossReach Perinatal Counselling Service	*No DoI submitted*

	Counselling North/West		
JH	Jo Holmes	BACP, Children, Young People and Families Lead	*Organisation response* Professional membership body for counsellors and psychotherapists across the UK, BACP would be strengthened following a recommendation for talking therapies as it would increase options for clients in Scotland and BACP members would likely be providing services
--		NES Programme for Parenting and Infant Mental Health,	*Organisation response* NHS Education for Scotland (NES) is an education and training body and a national health board within NHS Scotland. We are responsible for developing and delivering healthcare education and training for the NHS, health and social care sector and other public bodies. We have a Scotland-wide role in undergraduate, postgraduate and continuing professional development. The acceptance of these SIGN guidelines may have implications for workforce training and development needs to ensure practitioners are skilled and knowledgeable to meet the needs of the target population.
KB	Katie Borland	Policy Officer, See Me	*Organisation response* National programme to tackle stigma and discrimination
LC	Lindsey Cullen	Music Therapist, Mother and Baby Unit, Livingston	*Individual response* Employment as a perinatal music therapist through NHS Lothian. Employment as a music therapist through NHS Lothian. Livingston MBU being unique in having a permanent Arts Therapist.

LF	Lorraine Farrow	Senior Educator, Women, Children, Young People and Families, NES	*Organisation response* NHS Board - Education and training body in Scotland. Comments and recommendations would strengthen a consistent and collaborative approach between SIGN guidance and NES Resources and recommendations for PIMH practitioners and collaborative workforce. Where not aligned confusion to the Scottish workforce and families supported may become disconnected and ineffective.
LIMc	Lynn Ingram McFarland	Owner, Ingram Screening, LLC	*Organisation response* Ingram Screening is a consulting firm based in Portland Oregon. We focus on educating and training providers, clinics, and organizations in screening best practices and in creating working business models of screening for Perinatal Mood & Anxiety Disorders (PMADs). Our organization would be weakened following the recommendation of using solely the EPDS as a screening tool. It goes against everything that we stand for and educate against.
LN	Lindsay Noble	Lead Occupational Therapist, Leverndale Hospital	*Individual response* Non-financial personal interests - previous staff member in MBU, currently professionally lead/ supervise PMH occupational therapy staff in GG&C
--		The Royal College of Midwives	*Organisation response* The Royal College of Midwives is a membership organization and sees this Guidance as an opportunity for the RCM as a professional organisation to influence its members in terms of communications and dissemination of the contents and enable them to engage with current recommendations/ and the evidence base on Perinatal Mental Health
MG	Dr Mari Greenfield	Research Associate, The Open University	*Individual response* Nothing declared

PB	Paul Baughan	GP, NHS Forth Valley	*Individual response* Nothing declared
--		Parent and Mental Health Scotland	*Organisation response* Perinatal and infant mental health awareness and advocacy organisation. It would be a resource we could share.
--		Perinatal IMH Steering Group, NHS Dumfries and Galloway	*Organisation response* Nothing declared
SHS	Sarah Hallam Stewart	Change Manager- Perinatal and Infant Mental Health, Fife H&SCP	*Individual response* Nothing declared
SMu	Susan Munro	SLT Operational Lead (Mental Health & Learning Disability), NHS Fife Speech and Language Therapy Service	*Organisation response* We would welcome inclusion in local provision around peri-natal mental health to promote the best quality service.

Section 1. Please tell us about the way the toolkit is written. **Is the language and tone appropriate?**			
		Yes = 18 No = 2 Comments:	
		No. As a person who has BPD myself, I feel that it is unkind in your description of BPD in the first part of your drop down menu to end it with "This can lead to unusual behaviour, which can be distressing and may upset others." The person who is MOST affected by distress and upset due to bpd is the person EXPERIENCING it. The choice to focus here on other people makes it seem like you are talking about these mothers and parents as a problem for society to deal with, not as a person who is struggling in themselves. In addition, you make no mention of EUPD, Emotionally Unstable Personality Disorder - which is commonly the term used for diagnosis in Scotland, as far as I am aware. People such as myself have a diagnosis of EUPD not a diagnosis of BPD. Both terms should be mentioned.	The section has been rewritten to be more person-focused and includes an explanation that the term EUPD is also used. We have included information that people with BPD often self harm, which covers quiet BPD.

		You also make no mention of 'Quiet BPD' and how that presents.	
	TL	Yes. I like the use of the graphics and videos, it's very clear and concise. I would encourage you to continue to try and shorten the text to make it as accessible as possible.	Thank you.
	CM	Yes. About this tool kit section – states that 'the toolkit will be of interest to…' then lists a number of professionals, with 'people with a perinatal mental health disorder and their partners' coming last. I feel it would be better to have them listed first in the interests of person centred practice	Changed to: It will be of interest to people planning a pregnancy, pregnant women/birthing parents, those who have recently given birth, and their partners and families. It will also be of use to any health or social care professional involved in care of a women/birthing parent in the perinatal period.
	LM	Yes. An excellent tool to towards meeting the core principles of the maternal mental health pledge, easily accessible, easy to read with good concise language	Thank you.
	SHS	Overall, the Guidelines appear comprehensive and a really useful, well put together resource to share with colleagues and service users. Simple design is really effective and makes the toolkit easy to navigate. The graphics are clear and videos really useful, in terms of the sharing of lived experience and peer support.	Thank you.
	JH	Yes. Beautifully presented.	Thank you.
	VR	Yes. Good tone.	Language consistency has been checked.

		Language: vital to keep woman / women / mother / maternal, but also to use birth parent as well, where appropriate. This should be done consistently.	
	LC	Largely the tone and language seem appropriate. I would perhaps question the use of the word 'women' when referring who attends the mother and baby units, as some people who do not identify as women may find this exclusionary.	This has been amended to include birthing parents.
	KB	Clinical tone under the recommendations for healthcare professionals tab. These would be inaccessible for those not working/ trained in the healthcare profession. We support the need for these guidelines to be available to professionals and to the general public. We suggest creating an accessible version of the general guidelines on the public page to enable service users to realise their rights for collaboration over their own care. We would also suggest that the toolkit and the information presented could be split by audience: service users, practitioners, decision-makers, etc. and also by purpose: self-management, seeking support, providing support, etc. This will strengthen understanding and ensure that users are accessing information relevant to them. For example, the practitioner pages referencing jargon. It would be useful to create a separate resource for professionals to also seek information, e.g. guidelines to good practice within our See Me PNIMH good practice guidelines (these guidelines are specifically for those commissioning PNIMH services). Creation	This section is intended for use by professionals only. The introductory text has been revised to explain that there is a separate section for health and social care professionals. There is a separate section for professionals. The focus of the toolkit is to provide an accessible way to view the evidence-based recommendations in the guideline. Tools for workforce wellbeing etc, are outwith the remit of the guideline.

		of a similar resource for workers would contribute towards creating an open, inclusive and supportive organisational and clinical culture that challenges stigmatising attitudes. The resource should include tools and support that prioritise workforce wellbeing, further ensuring that colleagues can be open about their own mental health, access support and support each other. We would note overall the language and tone is appropriate but would suggest that pages should be reviewed by a diverse range of lived experience voices. We would flag that some words used are not inclusive of everyone accessing this document - for example 'realistic medicine'. This term was created as a strategic document to be used for those working within the sector as opposed to the general public. We would also flag further terms like 'mental health literacy' should be simplified and free from jargon- around 1 in 4 people in Scotland experiences challenges due to their lack of literacy skills (National Literacy Trust). The toolkit should ensure information is accessible for a wide range of people, free from jargon. We would suggest referring to NHS Inform as a good example of accommodating to different groups needs (for example, accessible language and information in different languages). We would flag that the information and tone should be amended under the personality disorders tab, with diverse lived experience voices given the opportunity for co-production. For example the definition	The toolkit was sent to a diverse range of people and organisations for review as part of the consultation exercise. Thank you, the language has been reviewed and will be assessed by the commission for plain language prior to publication. Much of the information on mental health conditions has been taken from the information on NHS Inform. Thank you for this feedback. We have completely rewritten the section on What is borderline personality disorder? and added at link to the relevant pages on the SeeMe website.

		‘Personality disorders are conditions in which an individual differs significantly from an average person, in terms of how they think, perceive, feel or relate to others. This can lead to unusual behaviour, which can be distressing and may upset others’ may read as stigmatising- with terms such as “differs significantly” and “may upset others”. Those with personality disorders already face increased stigma within mental healthcare services with users describing experiences such as not being taken seriously, then ultimately withdrawing from support. Service users may also feel additionally stigmatised when accessing this page. Our Scottish Mental Illness Stigma Study (SMISS) evaluated experiences of stigma of over 346 participants in Scotland with severe and enduring mental health conditions. Qualitative data from our SMISS study demonstrates experiences of stigma around personality disorders within mental healthcare. - ““Because of my BPD diagnosis, I have had crisis team staff hang up on me even when I’m feeling as though I couldn’t keep myself safe. I was discharged from my CMHT by a psychiatrist who never spoke to me once but decided to discharge me anyway. I have been called ‘attention seeking’, ‘manipulative’ by services. I feel as though mental health services don’t take me seriously because of stigma around my diagnosis.” We would strongly suggest amending this page to adjust for tone and language.	

		Yes. This is a welcome addition and an innovative way to communicate issues around mental health	Thank you.
	EA	Yes. I think the use of birth parent vs birthing parent needs to be reviewed. As well as parent/person. It is inconsistent throughout the toolkit and 'birth parent' typically refers to a biological parent rather than someone who has given birth.	The language throughout has been reviewed.
		Yes it flows well and has a good readability level	Thank you
	MG	No. It should be clear that - unless in exceptional circumstances - shared decision making refers to the giving of information, whilst the right to accept or decline treatment always belongs to the person who is pregnant. The first sentence says it is for women and healthcare professionals. It would be good to have inclusive language here. The tokophobia section refers only to women. There is evidence that trans men and non-binary people also experience tokophobia, and may have a different experience (ie, about healthcare professionals seeing/touching/discussing their genitalia). It would be good to have both inclusive language here, and information targeted at this population.	Wording amended: This shared decision-making toolkit is for women/birthing parents and their families. It is to help you discuss your mental health, and any support you may need, with your health or social professional during your pregnancy and after giving birth. The language has been changed to include 'person' as well as 'woman'.

Section 2. Please tell us what you think of the content. **Does the content help people understand what the latest research and good practice is in perinatal mental health conditions?**			
		Yes = 19 No = 3 Comments:	
		No. Regarding BPD - I feel it is imperative in the section talking about what psychological therapies are able to mention dialectical behavioural therapy (DBT), as well as other therapies t from SAShat can help such as schema therapy, mentalisation-based therapy etc. The lack of suggestions here make it seem like there is very little that can be done! I would also personally like to see (considering how difficult it is for even those with diagnosis to access DBT through NHS) a recommendation and link in that section towards DBT skills. Things like Opposite Action, Cold Water Therapy, and 'Both And' Thinking are skills which can easily be explained and taken on by individuals even without being able to access full DBT therapy through NHS Also in your healthy eating section there is weight stigma. There is a lot of knowledge and information out there about how weight stigma is what increases	The app reflects the evidence base which is not strong enough to recommend a specific therapy. As the experience of borderline personality disorder can vary greatly between people, we think it is more important to include the good practice point that people should have individualised support with access to psychological therapies. The focus of the guideline is support in the perinatal period, rather than a full review of mental health therapies. The link to the obesity information has been removed.

		the chance of complications for heavier or fatter birthing parents, not the weight itself. I feel the inclusion here further perpetuates this. There are doctors out there such as The Fat Doctor (Asher Larmie) and Dr Joshua Wolrich who are doing a lot of work to speak about this. It is akin to saying that Black mothers have worse outcomes and blaming their race rather than acknowledging the role of systematic racism leading to this. I would also like to see trans-inclusive language used. "mothers and birthing parents" "mothers and gestational parents", "fathers and non-birthing parents", "fathers and non-gestational parents". You touch on the latter but I assume it is a nod to same sex relationships and not trans inclusive language choice. Non binary parents give birth too, and with the increase in acceptance and awareness around gender diversity and indeed neurodiversity such as autism, more and more people who are giving birth will be gender diverse.	We have amended the terminology to include birthing parent.
	LIMc	Yes. It would be great to have a screening-specific section.	Screening is covered in its own section for health and social care professionals, and under 'Identifying when I need support'.
		Yes. Clear sections on the toolkit which makes it easy to navigate.	Thank you.

	TL	Yes, I like how brief a lot of the text is, and if you want more info you can click through.	
	SMu	Yes. Presenting of information in videos as well as in text supports different language abilities and preferences.	Thank you.
	MCS	Yes. What psychological therapies may help me? Add the link to the Matrix https://www.matrix.nhs.scot/ What is psychological birth trauma? - this is missing the key element that trauma is caused by feeling unsafe or uncared for rather than just by experiencing a medically complex birth. Identifying when I need support - there is a whole sentence missing I think. Planning a pregnancy - it cites Psychological birth trauma as an occasion to use the Tommy's resource for severe mental illness. I don't think most people would consider birth trauma as a severe mental illness? Wonder if the term is off putting? Section on suicide - NES resources from national suicide work may be of use:- Informed Level Resources Ask, Tell Animations - Adult Three educational animations that inform individuals working with adults about mental health, how to maintain this; the factors that can lead to mental distress or mental ill-health; how to have compassionate conversations which sets out how to support people who are experiencing mental distress	The app is based on the recommendations in the guideline. We have added a link to the matrix to the guideline. We have added that trauma can be caused by a frightening experience. Unsure what, but this section has been reviewed and revised. Trauma removed. For clarity on how to get immediate help, we have kept to the main contacts for members of the public in crisis.

		or may be feeling suicidal and help them seek help. Although these can be viewed on their own, it would be recommended that these are viewed as part of a wider learning activity. • Ask, Tell, Look After Your Mental Health. Understanding mental health and keeping mentally healthy - (open access: https://vimeo.com/338176495) • Ask, Tell, Have a Healthy Conversation supporting compassionate conversations with people who may be experiencing mental ill-health or distress or at risk of suicide -(open access: https://vimeo.com/338176444) • Ask, Tell, Save a Life: Every Life Matters suicide prevention and keeping people safe (open access: https://vimeo.com/338176393)	
	CM	Yes. A lot of the video clips are quite long (some in excess of an hour) whilst I appreciate the content may be really useful, this might be quite long for some people to watch.	We have added the running length to the longer videos.
	GA	Yes. Format is easy to read and understand for patients and carers, easy to access different sections.	Thank you.
		Yes. It looks very comprehensive without being overwhelming and would act as a good "one stop shop" to access up to date evidence based information.	Thank you.
	SHS	In the "About the toolkit" section it might be useful to specify the level of evidence, as this will be important when helping people come to decisions.	Due to the lack of research, most of the recommendations are based on low quality evidence or expert consensus. We have added an explanation of the symbols to the introduction to be clear that the recommendations are either based

		Section on recommendation for professionals is really useful. Links to assessments and interactive versions such as EPDS helpful for practitioners. In the section "What mental health service is available" it mentions Perinatal Mental Health Services and Maternity and Neonatal Psychological but NOT Infant Mental Health specifically, so this seems really important to add and also links to the infant pledge and best practice guidelines? It would be useful to highlight that there are Specialist Health Visitors and Psychotherapists as they are not mentioned under 'professionals who might help'.	on evidence or clinical experience, and the others are good practice based on clinical experience. The section for professionals has been added, along with interactive scoring tools. Infant mental health services are included in the section on bonding with my baby. In 'further information' we signpost to the Perinatal Mental Health Network Scotland which provides further links to services. It is not possible to include every health professional in the list of 'professionals who might help', this is just to give an idea.
	JH	Yes. Perhaps could have included something on dissociative disorder.	This is quite a rare condition and out of scope for the guideline.
	VR	No. My comments regard mainly the sections on bipolar. I am a lived experience support group facilitator with Bipolar Scotland. I have suggested various changes. 1. Mental Health Conditions > Bipolar Disorder > What is Bipolar Disorder Definition as stands is too vague. I suggest rather the following, which I have adapted from the definition given by bipolar.uk: 'People with bipolar disorder experience extreme mood swings and changes in energy levels. They will have periods of stability but can then go 'low' (into deep depression, sometimes with recurring	The description has been revised and more detail added.

		suicidal thoughts) or ‘high’ (experiencing hypomania, mania or psychosis). They can also experience a ‘mixed state’, with symptoms of depression and mania occurring at the same time. Episodes, which last lasting weeks or months, go far beyond most people’s everyday experiences of feeling a bit down or happy.' 2. Bipolar Disorder > Planning a pregnancy Can information be given here or another suitable place on breast-feeding and bipolar? I suggest something along the lines of: ‘You may wish to consider mixed feeding or bottle-feeding for your baby. This would allow you to optimise your sleep pattern. Disrupted sleep could potentially trigger a bipolar episode. Bottle-feeding would allow you to resume certain medications that keep you well.’ I think it important that mothers with bipolar be told it’s ok to veer from the ‘breast is best’ mantra. At present, some are made to feel that they are privileging their own health over their baby’s if they use formula. For a mother with bipolar, minimising the risk of a bipolar episode is the priority. 3. Bipolar Disorder > What medicines choices do I have? ‘pregnancy and breastfeeding’ comes up twice re. medication. The expectation is that mothers will breastfeed. Could a sentence be added to the medicines section: ‘Some mothers / birth parents may opt not to breastfeed.’?	We did not address the pros and cons of breastfeeding versus bottle when examining the evidence base, other than consideration of the safe use of medication. Therefore we cannot provide details of harms or benefits in the public-facing version, or make a statement advocating bottle over breast feeding.

		I welcome this reassuring blurb from the Royal Society of Psychiatrists website on Lithium in Pregnancy and Breastfeeding and perhaps some text like that would be good for the toolkit more generally: 'Although breastmilk is good for babies, the most important thing for your baby is that you are as well as possible. Not all women manage to breastfeed even if they want to. There are many different reasons for this. If you can't breastfeed because you need to take Lithium don't worry. Bottle feeding can have some advantages – and you can still have the skin to skin contact which is an important part of bonding with your baby. If you have a partner or family member staying with you, they can do some (or all) of the night feeds so that you can make sure you have enough sleep. This an important part of helping you to stay well.' 4. I welcome the section on Videos and Personal Stories 5. Bipolar Disorder > Information and Support Can Bipolar Scotland be listed above Bipolar UK? It works alphabetically. While Bipolar UK has more resources online, Bipolar Scotland provides the support groups in Scotland (Bipolar UK doesn't have that remit), and so the face to face and local support. The Bipolar Scotland blurb needs tightened up. We have had a recent discussion within the charity to use the term 'support group' rather than 'self-help group', although the website's still being tidied up:	Bipolar UK has been removed as the link to Bipolar Scotland is more relevant. Text amended to this suggestion. Thank you.

		(Original version in toolkit, with some grammar inconsistencies) 'Bipolar Scotland provide information, support and advice for people affected by bipolar disorder and all who care for them. They promote self-help throughout Scotland and informs and educates about the illness and the organisation.' (my suggestion) 'Bipolar Scotland provides information, support and advice for people affected by bipolar disorder and all who care for them. The charity offers support groups and peer support throughout Scotland; and informs and educates about the illness.' 6. Homepage > Keeping Well As well as Eating Well etc, can there be a subsection on Social contact / peer support? It is vital for pregnant women / birth parents and new mothers / birth parents that they meet regularly with others in a similar situation. A number of these structures were lost over the Covid period, e.g. antenatal classes. It is important that they be reintroduced. Parenting can be very isolating. Mothers with mental illness do need to feel integrated into society. Antenatal groups, mother and baby groups and toddler groups, library rhyme groups do this. There may also be support groups for mothers with postpartum depression in some areas. (There was one that my health visitor told me about in Bothwell in Uddingston, but it stopped prior to 2012.) Face-to-face is vital; online is not enough.	This is covered by the Support directory and advice in recommendations specific to the mental health conditions.

		Under the Sleep section, blurb I've detailed in Section 2, re. sleep and breast-feeding might have a place here. Thank you for giving these suggestions due consideration.	
	LF	Yes. To a degree, but requires wider known conditions as discussed previously	The conditions included reflect those included in the guideline remit.
	KB	No. We would flag that the clinical guidelines are not inclusive to the general public due to the clinical tone in which these are written. We would flag that there is not a lot of research available within the toolkit, especially taking intersectional stigma into account. We would suggest reviewing See Me's literature review, evidence based good practice guidelines and case studies to expand this further.	The clinical guidelines are intended to be for health and social care professionals so the clinical tone is appropriate. The sections of the toolkit for the general public are intended to be a translation of the clinical guideline into plain language rather than a document which extends to research from outside the remit of the guideline. The language has been edited and will be checked by the commission for plain language prior to publication.
		Good links to material/ resources- how well does it link to NHS Inform?	A lot of the text about the mental health conditions has been taken from NHS Inform
	MG	Yes. Mostly the toolkit is excellent. But it is really only applicable to cisgender heterosexual women. It would be good to include information about tokophobia and birth trauma in female non-birthing parents, tokophobia in trans men and non-binary birthing parents, gender dysphoria as a perinatal mental health condition, etc.	This has been added.

Section 3. What is your view on the amount of information presented throughout the toolkit?			
	LN	About right	Thank you.
		Too little. You need to give more self help information for parents. I believe you should also include sections for each mental health condition on normalisation, destigmatisation, and making people feel seen and understood in non-clinical speak. There should be a section around how to advocate for yourself with doctors. So often we can be made to feel like we don't know enough and that we don't have any choices and this can be particularly prevalent in the realm of birthing and in the realm of mental illness. If we want to truly empower parents then this should be included. In the keeping well section the first topic should be around looking after your mental health! Self care and how that is less the capitalistic stereotype of bubblebaths and candles, and is actually by looking at our unmet needs (such as safety, recognition, sensory regulation etc) and targeting our efforts there. It should mention how to find support in the community, how finding groups of parents can help, how there are often things like mother journalling groups, or birth trauma therapy, or sling libraries	The toolkit is a reflection of the therapies that have been recommended in the evidence-based guideline. The focus is on perinatal mental health, not all aspects of the condition. The recommended advice has been made clearer throughout. *This is* covered in the 'What is shared decision making?' section. The 'further information section' has been changed to 'Support Directory' and further advice on social support is included in recommendations throughout the toolkit. We have added LGBT Health and Wellbeing Scotland, along with some other resources Thank you for the suggestion.

		which are statistically proven to improve the mental health and bonding and attachment of both parents and their babies. You have a link for fathers and partners but only link to fathers network scotland. What about second parents who are non-binary or female? You should be linking to LGBT+ sites also like LGBT Health and Wellbeing Scotland.	
	LIMc	About right	Thank you.
		About right. Clear sections on the toolkit which makes it easy to navigate.	Thank you.
	SM	Too much A lot of information especially if unwell but the information is great.	Thank you for the feedback.
	TL	Too much.	Thank you for the feedback.
	SMu	About right.	Thank you for the feedback.
	MCS	About right. I did think that some of the film clips look long.	Some of the clips had been incorrectly labelled as minutes instead of seconds. This has been amended,
	CM	Too much. There is a lot of different tabs which, when opened open further tabs which can seem quite overwhelming.	Thank you for the feedback.
		About right.	Thank you for the feedback.

	GA	About right.	Thank you for the feedback.
	LM	About right.	Thank you for the feedback.
		About right. It is very comprehensive but the layout makes it easy to focus on specific areas of interest	Thank you for the feedback.
	SHS	About right. Really accessible info with lots of detail if this is needed.	Thank you for the feedback.
	JH	About right. It has a good variety of resources -the videos are relatable -one mentions DBT 'Dialectical behavioural therapy' (The Mind BPD video) but there's nop reference to this evidence based therapy in the resources	The focus on DBT has been taken out of the title. The video discusses a range of therapies that may help, in keeping with the good practice points in the guideline.
	VR	About right.	Thank you for the feedback.
	PB	About right.	Thank you for the feedback.
	LF	About right.	Thank you for the feedback.
	LC	About right.	Thank you for the feedback.
	KB	We would suggest condensing the information available on the tool kit. Generally, the information provided within the toolkit is useful and informative. Certain pieces of information in the toolkit are repeated (for example information on mental health conditions). Some users may find the level of text overwhelming and difficult to digest. We would suggest consulting with diverse lived experience voices to inform any changes to the information. We would also further suggest that videos should be broken down into different links and sections as some	We have repeated information to allow access through different routes, eg someone may be interested in a specific condition, or may want to know about specific therapies. Consultation on the toolkit was open to all, and sent to a diverse range of organisations for comment. The videos are links from external sources so we are unable to break them down or add transcripts if not available. Where a video is lengthy the time

		videos are over an hour long. This may be overwhelming for those accessing the page with users, perhaps missing key information from videos due to not being able to dedicate this time to listening. We support the availability of transcripts in some videos but flag that there are transcripts missing for others. We would suggest creating a transcript for each of the videos for accessibility of deaf users, and to allow users to scan the information at a faster pace. We would suggest that the section on treatment choice “planning your care” could be expanded further. Including more information of the treatments and the benefits/risks would be useful for parents to advocate for their own treatment as reflected within our evidence based good practice guidelines. This would provide service users with the information to take their preferred treatment route and empower them to navigate perinatal mental health services.	is given in brackets. We prefer to retain them so they are available for people who are interested and have the time to watch them. Options for treatments are in separate sections and under the specific conditions. We have added symbols to show which are recommendations from the guideline.
		About right.	Thank you for the feedback.
	EA	About right. I think it would have been helpful to have information on the evidence base behind group vs individual/1-1 interventions for different presentations. I would also have found it helpful to have more detail on tokophobia presentations.	There is no evidence on group vs individual 1-1 interventions. A new section on tokophobia has been added.
		About right. Could be less replication of paragraphs in different sections from previous sections	Thank you for the feedback.
	AMc	About right.	Thank you for the feedback.

	MG	About right.	Thank you for the feedback.
Section 4. How easy is it to navigate through the toolkit? **Eg, Could you find the information you were looking for? Could you get back to the home page?** **Is there any information you think should be given more prominence (eg higher up the menu)?**			
		Yes: 11 No: 4 Comments:	
	LIMc	Looks easy enough, but I know what to look for. If I was a suffering patient, it might be a little overwhelming.	Thank you for the feedback.
	EMH	There is a lot on here and it took me 4 clicks to get to the Inspiring Scotland 3rd Sector Directory - could they make access to these essential resources closer to the 'top' page	Inspiring Scotland is at the top level of the information resources section
		Clear sections on the toolkit which makes it easy to navigate.	Thank you for the feedback.
	TL	Yes, as mentioned elsewhere I think it looks good. There's one big gap though, the third sector. I'd like to see that given prominence for the impact that can have on a family. perhaps linking through to the Inspiring Scotland mental health database: https://www.inspiringscotland.org.uk/perinatal-mental-health-services/#anchor	Inspiring Scotland is at the top level of the information resources section

		Or to local third sector interfaces. I could give more info on this if you'd like to talk about it.	
	SMu	Clear layout and information is easy to find. Like that there are several ways to get to the same information reflecting different ways of thinking about "the problem".	Thank you for the feedback.
	MCS	I found it tricky to navigate - think it was because there are so many different sections under each topic and I found it hard to keep track of where I had started from each time I finished one of the sub-topics.	The toolkit has been restructured and some of the sections removed.
	CM	I found it easy to return to the home page, however the app can be difficult to navigate in that you click into one section which opens lots of other tabs which can take you further away from what you initially wanted to look at, especially if you are easily distracted.	There are ‘breadcrumbs’ across the top which are links to the pages that have opened.
		It was a little difficult to navigate through. Once clicking into a section, you had to undertake a series of Back motions to return to options.	There are ‘breadcrumbs’ across the top which are links to the pages that have opened
	GA	Very easy to navigate, headings very clear.	
	LM	No issues with navigation. Would give consideration to giving planning a pregnancy more prominence to promote preconception planning	We have added text to the front page to say it can help with planning for a pregnancy.
		I found it easy to navigate on my laptop but would hope it is equally easy to access by smartphone	Thank you for the feedback.

	SHS	Really good.	Thank you for the feedback.
	JH	Yes, it's well laid out, navigation is easy and leads you to interesting resources - for example, i typed in 'counselling' and came across the Muslim Women's Network	Thank you for the feedback.
	PB	It was easy to navigate	Thank you for the feedback.
	LF	The toolkit is okay to navigate but would be better if section for professional and the women Impact of trauma on psychological wellbeing & TI care	There are separate sections for professionals and women. This has been made clearer in the text on the front page.
	LC	After pressing home I found it a little difficult to navigate back to the toolkit for parents.	The different sections have been made clearer on the home page.
	KB	We would flag that peer support should be assigned its own tab. Our literature review identified that peer support was one of the key themes stated within our best practice guidance. Evidence revealed that women and their partners often feel isolated through stigma related to perinatal and infant mental illnesses, but that peer support can offer connection, learning and support. Peer support workers and volunteers provide valuable real life insights, individualised support, guidance and encouragement based on their own learning and experiences. We suggest an explicit emphasis of this as a valuable resource would be beneficial for those accessing support. We would suggest 'planning a pregnancy moved down' and 'keeping well moved up'. The website is titled wellbeing: Shared decisions	Good practice points on peer support and links to where people can get support are provided throughout the app. The Support Directory includes a specific section on support groups. We have added a sentence to the front page to explain that it can help with planning a pregnancy too, It is important for women with mental health conditions to preplan, particularly if taking medication, so would prefer to keep the structure as it is. We have tried to keep the title clear but concise

		about your mental health during and after pregnancy, the prominence of planning a pregnancy may confuse those who have been signposted to this and there is a risk they wouldn't explore further with the assumption of being signposted to the wrong website. Further, for those that are researching online who may be hoping to plan a pregnancy – the title of the website may deter them as they may not think that the information is suitable to their needs. Shared decision-making should also be given more prominence to be consistent with the name of the tool. We would suggest expanding this to showcase any commitments that the NHS has towards shared decision making. Within this section, we would suggest including information such as: "understanding your rights". This should include recommendations from the Mental Health Law review e.g. signposting to independent advocates. This will empower service users to realise their rights – which is a key vision within the mental health strategy and contribute towards shared decision making. We would also include stigma and self-stigma as a key page within this tool. Our SMISS qualitative findings emphasise that some people struggle to find the words to express how they feel due to internalised self- stigma and anticipated experiences of stigma and discrimination, which can result in assessments not providing a clear overview of how they feel. See Me's PNIMH literature review also emphasised that there a reluctance to seek help for, and, be	The title of the toolkit has been changed. The toolkit offers an opportunity to inform a person and empower them to have knowledgeable discussion with their healthcare professional, which aligns with the Realistic Medicine definition of a shared decision tool. We hope that the toolkit can help to break down stigma but do not feel that it needs to have a specific section to address it. The toolkit focuses on the clinical recommendations from the guideline and positive advice on health and wellbeing during pregnancy.

		diagnosed with a perinatal mental health illness (for example, not wanting to emotionally burden families by sharing their symptoms; out of fear of losing custody of their child(ren). Introducing a stigma section on the website will encourage services users to express feelings of self stigma and empower them to seek support. This information will empower service users to understand that mental ill health is not a sign of weakness, promote helpseeking behaviour, and help challenge self-stigma where it occurs.	
		The issue of Stigma could be featured more prominently	We hope that the toolkit can help to break down stigma but do not feel that it needs to have a specific section to address it. The toolkit focuses on the clinical recommendations from the guideline and positive advice on health and wellbeing during pregnancy.
	EA	No difficulties navigating the toolkit.	Thank you for the feedback.
		More info on Perinatal trauma More info on Maternal OCD Could there be more of a BAME voice and LGBTQ plus voice? Could there be more for young parents e.g. FNP	We have rewritten the trauma section so it includes more information. We have included a description of OCD, recommendations for treatment and links to further information. We have included information available for minority ethnic groups and LGBT parents throughout the toolkit and have made the sections in the support directory easier to find.

			We have included links to information and support for young parents where possible.
	MG	Navigation is okay	Thank you for the feedback.
Section 5. Do you have any comments on the look of the guideline (eg colours, images, overall impression)?			
	LN	More images may be helpful	Thank you for the feedback.
	LIMc	Looks good.	Thank you for the feedback.
		I like the colours and images.	Thank you for the feedback.
	TL	I really like the landing page and how it's laid out.	Thank you for the feedback.
	MCS	My impression - from the colours and the layout I think was that it was a bit old fashioned.	Thank you for the feedback.
	EMH	Realise this is a mockup right now so I won't get too bothered by the images which did not really jump out /inspire me however overall it felt easy to use/navigate	Thank you for the feedback.
	CM	I think the order of the tabs should be different, eg have the 'about this tool kit' section first as an introduction, then perhaps the making notes tab so that users are aware of this early on and can take notes as they go.	The about the toolkit section has background information about how the guideline was developed rather than information on mental health conditions, so we think this should stay at the end. We have added more description of the content and aim of the toolkit in the landing page.
	GA	Colours appropriate (also helps with navigation). Use of videos also helps to illustrate the information well, positive to provide different formats for patients/carers to use.	Thank you for the feedback.

	LM	Overall impression that this guideline is making information easy to access and providing a starting point for important conversations	Thank you for the feedback.
		I think it is attractively presented and have a positive overall impression	Thank you for the feedback.
	SHS	Love the graphics and design- Nothing to add	Thank you for the feedback.
	JH	It is so well put together - what a fantastic resource	Thank you for the feedback.
	LF	Visuals are inviting	Thank you for the feedback.
	LC	I think it looks very inviting and colourful without feeling overstimulating.	Thank you for the feedback.
	KB	Colourful and accessible – operates in a user friendly way	Thank you for the feedback.
		The images are vivid and make reading easy	Thank you for the feedback.
		We like the sections where parents put in questions to ask at appointments and the use of videos and blogs. Text Some text stops abruptly – e.g. when talking about assessment but might be my server. Can you have the info in different translations for sight impaired parents?	Thank you The text has been revised throughout. The toolkit is compatible for use with technology for translations.
	MG	I like that it is not overly pink or pastel	Thank you for the feedback.

Section 6. Any other comments			
	LN	The session on "Keeping well" it may be useful to have something here re routine/ activity/ co-occupation with baby. This area can overwhelm mums- something around rationalising and prioritising along with normalising the difficulty in routines can be difficult?	We have added more information around bonding and links to Parent line for further advice.
	EMH	When/how will the expectant parent/parent be given access to this - at what points in the journey will healthcare professionals be reminded (and have the time) to show this resource to them/help them navigate - feedback from many parents is that they have been too overwhelmed around birth/just after to be able to retain information/accept support so how can we ensure they are reminded of these resources and often healthvisitors/midwives have very little time to spend on these activities - has this been considered in terms of the rollout/implementation plan.	Publication of the guideline and app will be disseminated to all health boards and through the MCNs and professional networks so health visitors and midwives should become aware of it. It is also hoped that it will be added to Baernet.
	EMH	Understand why they want this to be shared (shared decision making), however it could overwhelm a parent having access to such much info - perhaps this is more about a less busy front page /the layout of the front page?	We have tried to split the toolkit into sections so that it is easy to go direct to the area of relevance and information can be read in chunks.
	LIMc	Thank you for working on this!	Thank you

	SM	Thank you great tool	Thank you
	TL	Again, I'd like to see some prominence for Dads and other non birth parents, to talk about the importance of the family.	We have added resources for dads and other non birth parents where available throughout the toolkit and made the section in the Support Directory more prominent.
	CM	There is a recommendation for healthcare professionals tab but not for other professionals who may be involved i.e. social workers, early years workers, addiction support, third sector etc. Under the What MH services are available if I need support? The video clip re CPMHT lists some of the professionals in teams but doesn't mention OTs, Nursery nurses or social workers	This has been changed to health and social care professionals. The video clip is from an external source. We cannot list everyone, but it gives the user an idea of the multidisciplinary care available.
	SHS	Would like to see Infant Mental Health provision more embedded as a service/ care option throughout the toolkit, particularly in the section "What services are available".	Infant mental health services are included in the section on bonding with my baby.
	LF	Missed opportunity to better collaborate with women in developing a person-centred plan of care. Area for shared decision making is basic. Would be more effective if an agreed template is completed that can be transferred into the maternity Badgernet system. Providing a national approach that is consistent across the services, platforms and varied mental health conditions.	The toolkit reflects advice from the recommendations and signposts to other support. It is outside the remit of the guideline to produce a reporting template. Badgernet is not used in every health board.
	KB	We would flag that the title "shared decision making toolkit" is misleading. This name would indicate that it is a toolkit for service users to ensure that their rights are fulfilled, for example, information on a shared	The toolkit provides an opportunity for people to have an informed discussion and choice about their care. This is in line with the Realistic Medicine

		decision making framework that practitioners must adhere to. The toolkit more reads as an information website for those that would benefit from further reading on conditions and managing pregnancy/birth as opposed to empowering service users to collaborate on decisions of their own care. We appreciate the clear commitment towards shared decision making and suggest that the toolkit present more practical ways in which shared decision making is achieved. For example, making suggestions such as regular involvement of family/carers/advocates when reviewing care plans, with the permission of the service user. We would also flag that under the “mental health conditions” tab, surviving suicidal thoughts is listed. We would flag that suicidal ideation is not a mental health condition and can be triggered by distressing life events and circumstances. We suggest removing this from the tab and creating a tab that is separate to this or more suited to the information available – such as the “identifying when I need support tab”. It may be useful to put a link within the mental health conditions tab that highlights that suicidal ideation is not a mental health diagnosis but there is help/ information on the link attached. We would suggest expanding the toolkit to account for cultural differences, such as different meanings/ understandings and stigma centring around the word “mental illness”. Addressing language differences and barriers would lead to more effective conversations	definition of shared decision making. We have however amended the title to be shorter and more understandable for members of the public. Surviving suicidal thoughts is included in both mental health conditions and Identifying when I need support. The app is a translation of the recommendations on screening and treatment in the SIGN guideline and developing further is outside the remit. We have included links to resources for further support, and include videos or people talking about their personal experiences.

		about mental health. Participants within a study (Adzajilc, 2022) spoke of mental illness in terms of being a ‘curse’, ‘insanity’ ‘possession of the devil’ and associated it with violence and danger. We would suggest involvement of diverse lived experience voices for the design of the toolkit and website to ensure that they meet the needs of diverse groups. We would suggest that it might be beneficial to apply real life case studies/personal stories. For service users, being provided with a lived experience account can help to tackle the self stigma and internalised shame that is reported. Identifying with peer support or engaging with others stories contribute towards reducing stigma, concerns around judgement and fear that the child will be taken away. These would help increase awareness of mental health problems, reduce mental health stigma and encourage help seeking.	
		In the section on ‘Identifying when I need support’, at the bottom of the page, there is a link to an MMHA video called Jenny’s story. There is a typo in the credit to MMHA – calling us the ‘Maternal Health Alliance’ and omitting the word ‘Mental’ before Health.	Amended, thank you.
		Areas to improve Videos- several about mental health cut off after a minute (e.g NCT, Best Beginnings). Might be the server? Local offers of support: Perhaps need a caveat to say that each area will have a range of differing supports	Thank you. The videos are only a minute. We have taken the incorrect timings out. The app is a reflection of the evidence-based recommendations on what support should be available.

		eg stand alone/ dispersed/ types of therapy e.g. IPT not available in some areas Birth trauma- could you mention that it is eye of beholder/ the person's perception of the birth experience rather than the events as some women may have had what seemed to be a normal delivery. Is it best to say Perinatal trauma that psychological birth trauma to encompass the whole period e.g. in pregnancy (hyperemesis) and post natally (child in neonatal) No mention of EMDR in regards to birth trauma. Also description of birth trauma as a severe mental illness- how helpful is this? What about impact upon dads/ partners/ infant / siblings? Could there be more guidance on what Midwives and HV should be looking out for/ what questions to ask to screen for birth trauma? Could there be more on common intrusive thoughts which can cause concern in women and also clinicians which are related to OCD than actual risk Depression: No mention of Silvercloud Computerised CBT or similar	We have added What someone feels to be traumatic or difficult can differ from person to person. Details of psychological therapies have been added. Severe mental illness has been removed. This was outside the scope of the evidence review for the guideline. We have signposted to further places for support for dads/partners. The City Birth screening tool is recommended for HVs and midwives. This is in the section for healthcare professionals. A section on intrusive thoughts is included. We do not have the evidence to recommend specific CBT packages. Silvercloud, sleepio and Solihull are not an open access resources. Rather than listing all organisations we have signposted to more extensive directories, such as Inspire Scotland.

		Add more Support organisations- Breathing Space, PANDA Include organisations that offer peer support such as Dad's Rock, Homestart Bereavement and Loss- Can there be a section on this and resources eg Sands Keeping well- can you add Sleepio app to this? Bonding- can you add the Solihull resources? Infant Voice Charter Dads/ Partners Can you add more for partners and dads BAME women Is the BAME voice heard throughout this guidance? Social factors such as poverty, homelessness, seeking asylum, young parents Include supports for families whose children have additional health needs Include more info for women who are neurodiverse/ hearing or sight impaired. Include more in the role of Occupational Therapy e.g Behavioural activation	Solihull courses are not free to access. Dad's Rock added. Available resources for people from minority ethnic groups have been included. We agree social factors are overwhelming, but outside scope and adding further information may make the amount of content overwhelming. Occupational therapy was out of scope for the guideline. The advice in the recommendations is applicable to people with disabilities. In the guidance for healthcare professionals an individualised approach is encouraged. A link to Relationship Scotland has been added.

		Support for women with ID, Physical disabilities. Links to Relationship Scotland for couples/ individuals	
	AMc	Toolkit has a lot of potential, looks great, interactive. Would be highly welcomed by professionals and patients	

Second consultation

The toolkit was revised in light of the comments from the first consultation, and further aligned to the finalised recommendations in the main guideline.

For a final check on the revisions a focus group meeting was held on Tuesday 9 January. It was attended by a representative from Homestart Scotland and two representatives from Bipolar Scotland.

The toolkit was also circulated to the guideline development group for final comments.

Focus group feedback

		Clear, easy to navigate. Like that its also an app. Clear colour scheme.	No action required
		Not seeing: what are your rights	A link to the Mental Welfare Commission Pathway to Patient's Rights in Mental Health Services has been added to the section on Identifying when I need support.
		Support in MBU – add links to 3rd sector, eg HomeStart	Covered in Support section.
		Include a section with common questions people will ask The common or top questions we get asked are (answers below we give so it's a starting point!) 1. If I ask for help will my baby be removed? ABSOLUTELY NOT – Asking for help is the bravest and kindest thing you can do for you and your baby. If you need more support that a health	The purpose of the toolkit is to reflect the recommendations in SIGN 169. The editorial team felt that this was outside the remit of the guideline so it has not been included.

		professional can give, or there are more environmental or social reasons for your illness you may get more support from the children and families team. 2. I'm in crisis and I can't cope – what do I do? Firstly, are you and your baby safe? If not you can go to your nearest GP surgery or hospital or call 999 and get immediate help. If you are experiencing a mental health crisis then ask a trusted adult to help you with your baby and get them to call the GP, your mental health team or the local hospital for advice of where to start. 3. Where do I start – there's too many people listed? Who do you trust with your health – usually it's the GP, Midwife or Health Visitor and those people can put you on the first step of the pathway. 4. I haven't had mental health problems before – is it the babys fault? No – its never the babys fault if you are struggling. Its often because our bodies change so much during pregnancy, through birth and after our babies are born. Sometimes it can also be because we have experienced something traumatic or experienced an injury. Its not your fault either and you deserve help. 5. My partner isn't right – they had the baby and have become like a robot? If this has come on very suddenly or recently after having your baby then this is an emergency for	

		getting some help for them. Call your GP and ask for an urgent appointment. If this has been slow over time then have you tried speaking to them about this? How do they feel? Is it worth having a chat together with the Health Visitor?	
		Not enough on neurodiversity. If neurodiverse have a conversation about how drug therapies may have a different interaction.	This is outside the remit of the guideline. No resources were identified specifically on perinatal mental health in neurodiverse people.
		Care experienced – won't have same support network. Here's some support you could get.	Links to information for care experienced people added to support directory
		Clear, not overwhelming as sections are collapsible. Videos and blogs are helpful.	Thank you
		Bipolar Sodium valproate is too far down the page. Most risky drug to be taking so this should be front loaded/made more visible.	Mood stabilisers section has been moved ahead of antipsychotics
		Section on crisis – hard to find. With common questions this could be highlighted. Crisis section should be more prominent.	The Crisis section has been given a separate tile on the home page
		App allows for feelings. Could it be extended to concerns, issues, physical symptoms? Eg bipolar impact with insomnia. Make wider than feelings.	Amended the intro to: You can use this space to write down how you are feeling, any emotional or physical symptoms you are having, and any issues or questions that you want to discuss with your healthcare professional.
		Explanation of R and GPP. Not clear. Because expert opinion of the group is included in both.	Reworded to: R - a recommendation based on research evidence, or through expert opinion if there was no evidence. GPP- suggestions for good practice based on the experience of the guideline development group.

		Breast feeding. Add destigmatisation of choosing not to breast feed by emphasising the risks, eg lack of sleep may trigger a bipolar episode – its in the guideline so make clearer in public version.	The toolkit already says that changes to routines and lack of sleep can trigger relapse. We did not address the pros and cons of breastfeeding when examining the evidence base, other than consideration of the safe use of medication, so we cannot provide details of harms or benefits in the public-facing version, or make a statement that would advocate bottle feeding over breast feeding.
		MBU section and MWC access – sounds good but number of units is limited. People concerned that they will be sent to a unit far from home. Be honest about the availability rather than implying that it is freely available.	We have added: If, for any reason, you don't go to an MBU, you may be admitted to your local hospital. Your healthcare professional can give you more information on what's available locally.
		URL is long but clear – people will understand it.	No action required
		Check consistency of capitalisation of names throughout text.	Done as part of the proof read.
		Do a leaflet with a QR code for welcome packs.	We have created a leaflet that can be printed from website.
		Many people who use Homestart don’t have a smart phone or computer access. The toolkit can be used with a support worker so they can look at it together but would be helpful to be able to print pages out too.	We have added a print button to each page
		Add - When you go to GP can you request a referral to a perinatal mental health team.	This isn’t how it works. There are criteria for referral for input from the perinatal mental health team and it would be misleading to suggest anyone can get referred. The GP assesses mental health and decides whether or not to refer.