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**Patient and carer involvement approaches**

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| **Approach** | **Description** | **Benefits and when to use** | **What you will need** |
| **Engagement events** | An event based in the local community with 15-30 participants. Participants tend to work in small groups on set discussion topics, although whole group discussions can also be used.An excellent way to generate broad discussions with a wide range of people. | Good for gathering broad range of insight or ‘temperature checking’ an idea.You will hear from a wide range of people, which will generate lots of discussion and lots of ideas.It’s worth trying to capture al ideas and ‘car parking’ these even if they’re not relevant to the project – as it’s all valuable insight that can be banked and used to help inform other work.You can use a range of activities within this including individual reflection, pair work, small group work. | * 1 or 2 lead facilitators including support for facilitating table discussions
* Consent forms – completed and signed
* Terms of use (how you will use, retain and store the conversations captured)
* Flip chart/s
* Paper/pens
* Post it notes
* Recording equipment (audio) to capture conversations – but you would be wise to gain additional opt in/opt out consent for this
* Photography – for promotional use – as above gain additional specific opt in/opt out consent
* Feedback to participants after the even with a follow up of how their data/input has been used
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| **Focus groups**  | Small groups of 6-12 people (8 is usually an ideal number anymore than 10 can be difficult to manage) focusing on a specific issue or topic. Can be helpful for speaking to hard-to-reach groups if you are struggling to engage with them at wider community events. 1 lead facilitator and a note taker required – although you may benefit form a support facilitator with a number above 8 – just to ensure that those lesser heard voices are picked up. | Can generate very detailed discussions and allows for detailed note capturing.Can be held face to face or online.Online focus groups provide an element of comfort and security for some people who will more openly speak up if they’re in their own environment or are able to turn off a camera. Allows everyone the chance to have their say and be heard Opportunity to hear from a range of individuals with diverse experiences. | * 1 lead facilitator and a note taker although you may benefit from an additional support facilitator with a group of more than 8, to ensure the lesser heard voices are actively encouraged to speak up.
* Consent forms – completed and signed.
* Terms of use (how you will use, retain and store the conversations captured)
* For face to face focus groups it’s helpful to give out paper and pens to all participants so they can write down any points they may want to raise.
* Post it notes.
* Recording equipment (audio) to capture conversations – but you would need to gain additional opt in/opt out consent for this.
* With a video call focus group you can use the record function – but gain written consent before the group meeting happens – don’t rely on the chat function for consent.
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| **Interviews** | A one-to-one meeting (or a very small group discussion) designed for a specific purpose or objective. | Good for building trust and rapport.Easier to obtain individual perspectives and ensure everyone gets a chance to have their say without following the crowd/what the majority say.Some people are more comfortable sharing their opinions in a one-to-one setting than a group setting Can generate very detailed feedback  | * Consent forms with right to withdraw clauses explained.
* Audio recording (or record via teams or zoom with pre consent)
* A confidential and comfortable space to hold the interview where there will be no interruptions
* Pre reading of the questions can be helpful for the interviewee – so provide these ahead of the interview where possible.
* The opportunity for the interviewee to ask any questions before and after the interview.
* Communication support if needed – for the interviewee.
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| **User/Reference Groups** | User or Reference Groups are ongoing advisory groups of a selected small group that meet over a period of time for the purpose of achieving specific objectives – and should link into decision making groups. A relatively formal recruitment process is usually used and the membership is selected to represent different elements of the local population. Requires ongoing staff. Commitment to support, facilitate and administer the group. Good facilitation is important. | Helps build a sense of partnership and gives patients and carers a sense of ownership and empowerment.Creates the opportunity for ongoing, meaningful involvement  |  |
| **Patient Representatives** | Two or three service users are selected to be representatives of the larger population.They sit on decision-making groups alongside professionals. This level of involvement requires ongoing support and development/training to be effective. | Adds a service user perspective right where decisions are made. Encourages equal partnership working.  |  |
| **Online networks** | A network of people who are willing to be engaged in an ad-hoc way, mainly via email although a dedicated and closed social media platform – such as Facebook or WhatsApp could be used as long as consents/information/rules are managed appropriately. These people can also be invited along to focus groups etc. as appropriate. | An efficient and cost-free way of keeping in regular contact with people and maintaining relationships with those who want to be engaged in an ongoing way.  | * A password protected and secure system for storing and retrieving personal data.
* GDPR (and Data Protection Act 2018) compliance measures in place, consents gathered (and updated every 2 years) for storing and retrieving data.
* Moderators for social media groups.
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| **Questionnaire** | Gathering feedback via survey – either online or on paper. Questions can also be asked in person or over the phone | Useful for accessing/collecting larger amounts of feedback. Data is often easier to analyse. Online surveys can be cost free.Can be a quicker form of engagement – both for service provider and service user. |  |