

SUCE

 | Service User & Carer Engagement

The Faculty of Health and Life Sciences recognises the unique experiences, skills and abilities of service users and carers and is committed to strengthening service user and carer engagement in all aspects of health and social care programmes in both undergraduate, post graduate provision and research.

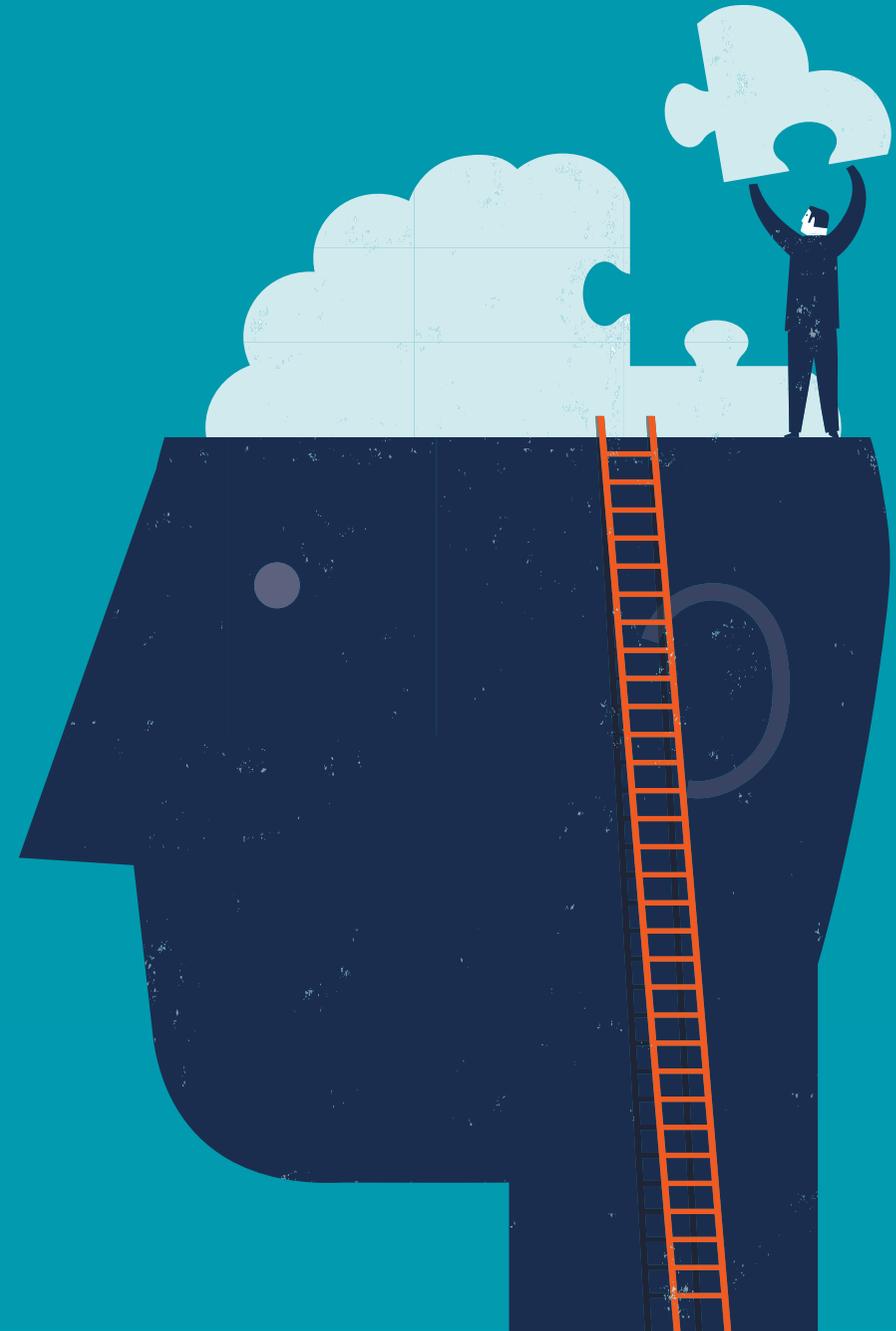
Service user and carer engagement in higher education is becoming an increased facet of course delivery, particularly within health and social care programmes regulated by the Health and Care Professions Council (HCPC) and the Nursing and Midwifery Council (NMC).

This toolkit has been produced in collaboration with service users and carers, voluntary organisations and academic and professional service staff in the Faculty of Health and Life Sciences.

[Click here to Enter the toolkit](#)

Disclaimer

Use of this toolkit is subject to the terms and conditions of a licence which can be found [HERE](#). By accessing and using this toolkit you are agreeing to adhere to these terms and conditions. If you are not prepared to agree to the terms and conditions, no permission is granted to use the toolkit



SUCE | The Lived Experience in Health and Social Care Education

Toolkit Framework

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What's the purpose of the toolkit?

This toolkit aims to provide learning resources that encourages course teams and researchers to consider and implement the key issues required for service user and carer engagement within the Faculty of Health and Life Sciences.

The toolkit aims to:

- Be a useful reference point for Service User and Carer Engagement
- Be clear about the expectations and responsibilities when engaging with Service Users and Carers
- Facilitate a consistent approach to Service User and Carer Engagement

The learning resources will outline important points of reference and suggest strategies for ensuring meaningful and purposeful service user and carer engagement.

I would like to say a huge thank-you to all the people that have contributed to this toolkit. Without all of your time, energy and commitment to Service User and Carer Engagement none of this would be possible. I hope you find this a useful resource. If you require further information about the toolkit, service user and carer engagement please contact:



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Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
	The ladder of Involvement					

Initial Engagement

Before you begin to work with service users and carers there are a number of things you need to consider

Where to recruit?

It can often feel daunting to know where to access service users and carers for your courses.

The faculty of Health and Life Sciences has a database where service users and carers have registered their interest to be involved in activities with the faculty.

To access the database you will need to complete [the database request form](#) and email to the Health and Social Care Unit.

It is also a good idea to:
Speak to your colleagues as they may be able to suggest individuals or organisations that could help.

Speak to relevant clinical or placement areas you have contact with to find out if they might know of individuals or groups that could help.

The Coventry Health and Social Care directory is a very useful resource for finding voluntary groups in Coventry. <http://directory.vacoventry.org.uk/>

The Warwickshire Community Directory also provides this information in Warwickshire. <http://www.vconnectssystem.org.uk/warwickshirecommunitydirectory/>

Make contact with relevant voluntary, advocacy groups and attend one of their meetings, so they can get to know you and build trust.

Distribute some flyers indicating opportunities for service users and carers to become involved in your course. This could be in GP surgeries, the library, clinics and community centres.

The Initial Engagement Checklist

[Click here](#) for areas that will need to be discussed in your initial engagement meeting.



TIP

It is important that you take some time to think and plan ahead in relation to the type of service user and carer engagement activities that you are considering.

TIP

It is important that you take some time to think about What you are considering? Why? and How will it be achieved?

TIP

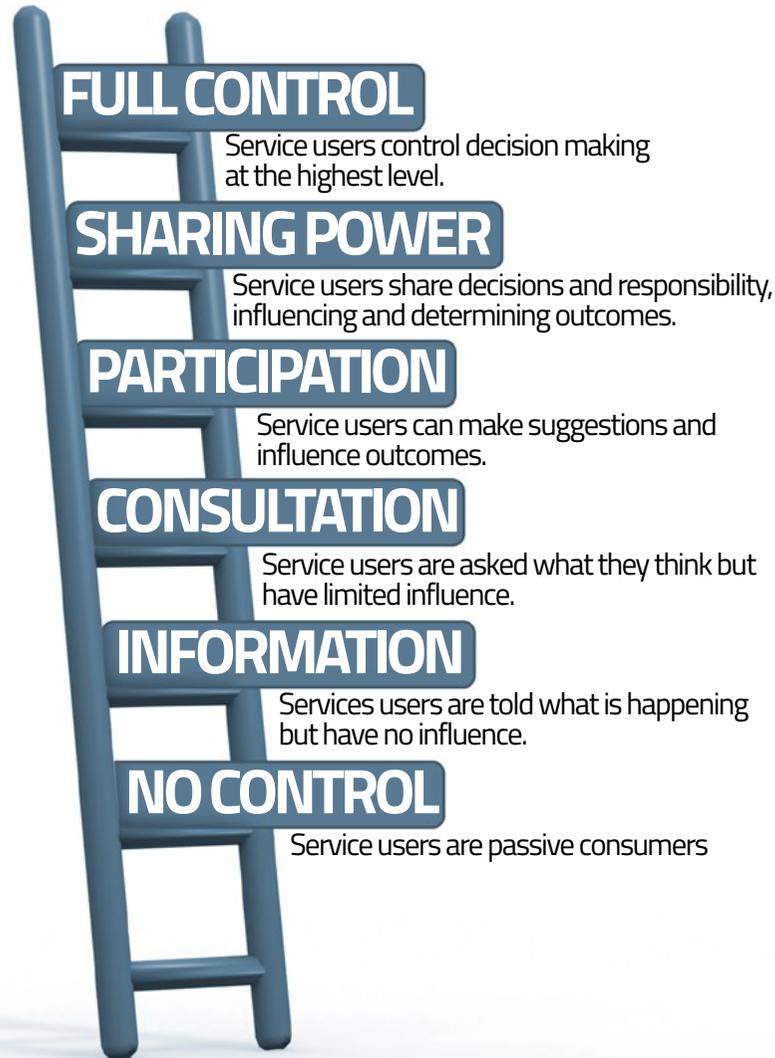
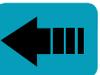
Once you have made contact with individuals or groups who are interested in becoming involved with the faculty they can be encouraged to join the Faculty of Health and Life Sciences. ([Click Here](#) to access SUCE application form)

TIP

Try to follow-up service user and carer interest in a timely manner



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The Ladder of Involvement

Whilst thinking about and implementing service user and carer engagement activities it is suggested that for each area of activity you consider you refer to the Ladder of Involvement.

The Ladder of Involvement is a useful way for you to:

- Be clear about your rationale and how you are working with service users and carers
- Plan how you would like to work with service users and carers
- Review how you are currently working with service users and carers
- Think about how meaningful your service user and carer engagement activities are for service users and carers and students
- Avoid tokenistic and “tick box” service user and carer engagement
- Think about, plan and make suitable time allowances for the level of service user and carer engagement that is being considered and implemented

Click below for information about SUCE models of involvement

<http://www.hpc-uk.org/assets/documents/10003A08Serviceuserinvolvementinthedesignanddeliveryofapprovedprogrammes.pdf>

Support for Service Users and Carers

It is important that any service user or carer that you will be working with receives appropriate support and guidance. The service users and carers that you come into contact with will vary, they may be new to the university, unfamiliar with your department; though some may not be, its best not to assume.

An initial 1:1 Meeting is Necessary To:

- Get to know the person's health and social care needs and their support requirements
- Clarify what they want and don't want to contribute to
- Become informed of their involvement activities and experiences
- Discuss reimbursement and remuneration
- Discuss proposed activities and how this might be achieved.
- Provide information leaflets to complement discussions.
- Clarify any issues regarding accessibility and attending the university

Peer Support

Sometimes service users and carers can feel a little nervous, particularly if doing something new. It can be helpful if they bring a friend with them or are accompanied by another service user or carer who has previous experience within the Faculty of Health and Life Sciences as support.

Orientation and Induction

Following the 1:1 meeting all parties should have:

- A clearer idea of what is required
- An understanding of each other's needs
- Agreed expectations
- An agreed point of contact for the service user or carer: name, email address and telephone number
- Completion of all the relevant documents

TIP

You may need to check the room layout and check to see if there is good accessibility to the building and the room that your are using.

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Engaging Service Users and Carers in: Assessment

There are a number of different ways that service users and carers can contribute to the assessment of students and enhance the learning process

TIP Involvement in assessment can be both **summative and formative**

Examples include:

- Student oral and poster presentations
- Objective Structured Clinical Examinations (OSCE's)
- Written work completed by students
- Simulation and role-play activities
- Students performance in practice settings

Click below to find out more

Preparation

On the Day

Feedback and Evaluation

Service users and carers will require:

- An introduction to the topic and the aim of the assessment
- Input to the development of the assessment criteria if possible
- An understanding of the assessment criteria being used
- Clear information and guidance about their role and what they are looking for in relation to the assessment activity
- Guidance and support on giving feedback to students
- Information about the student group and how many they are expected to assess.
- Clear information about the format of the day: arrival times, meeting place, expected time to finish
- Dates to be sent out beforehand so they are clear when they are required.
- Relevant hand-outs, assessment criteria are emailed beforehand and available on the day.
- A visitor car parking permit requested if this is needed
- Someone to meet and accompany them to the allocated room on the day.
- A contact person to inform of any changes or issues that may arise on the day.

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- Preparation
- On the Day**
- Feedback and Evaluation

- Service users and carers may be a little anxious and arrive early on the day.
- The person who meets and accompanies individuals to the room will need to be prepared to go over the process and answer any questions.
- Ensure they are offered a refreshment and are informed of where the nearest toilet is located.
- Ensure that the necessary forms are available and completed for remuneration and reimbursement.

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On the Day

Feedback and Evaluation

- Feedback and evaluation is required from all parties: service users and carers, students and academic staff. It's ideal to receive immediate feedback and evaluation from service users and carers involved. If this is not possible make contact or arrange to meet up if necessary
- Feedback and evaluation from students is important and is best completed at the end of the session. If this is not possible make arrangements with the group to follow up. It's important that the service users and carers are given feedback and evaluation of their contribution to the activity
- All of this information can be used to learn lessons and help to inform future teaching and learning activities

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Engaging Service Users and Carers in: Curriculum Development/Reviews

Service users and carers need to be actively involved in curriculum development and reviews right from the start. It's important that feedback and evaluation is sought on the previous curriculum and this information is used and applied to the new incoming curriculum.

Once consultation on the previous curriculum is completed, it's good practice for you to demonstrate how the information collated has been used to shape the new curriculum "You Said, We Did" can be a useful framework for doing this.

TIP You may need to check the room layout and check to see if there is good accessibility to the building and the room that your are using.

TIP Service users and carers make positive contributions to curriculum events. For their presence to be meaningful and effective they will need to be adequately prepared.

Click below to find out more

- [Preparation](#)
- [Preparation Tips](#)
- [On the Day](#)
- [Feedback and Evaluation](#)

Service users and carers will require:

- Information about the purpose of the day
- An agenda of the day and how long they will be needed
- Relevant course documents/information to be sent before the event in a timely manner
- Information about what is expected from them
- Information regarding how many people will be present at the event
- Potential questions that may be asked of them
- A visitor car parking permit requested if this is needed
- Arrangements made regarding what time to arrive
- A named person who will meet and escort them to the event
- A contact person to inform of any changes or issues that may arise on the day

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TIP A pre-meeting with the course team or a member of the team is a good way to ensure all the preparation needs are addressed.

TIP Service users and carers are increasingly becoming part of curriculum reviews. Here is a list of potential questions that reviewers may ask about SUCE in your course. [Click here](#) to access it.

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- Meet the person on the day and accompany them to the room
- Inform them of any changes to the agenda
- Ensure that any anxieties or questions are answered and that they are ready for the event
- Ensure they are offered a refreshment and are informed of where the nearest toilet is located
- Ensure that the necessary forms are available and completed for reimbursement of expenses

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Preparation

Preparation Tips

On the Day

Feedback and Evaluation

It's ideal to receive immediate feedback and evaluation following the event from service users and carers involved in the event. If this is not possible make contact or arrange to meet up if necessary. It's important that the service users and carers are given feedback and evaluation of their contribution to the event. All of this information can be used to learn lessons and help to inform future curriculum events.

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Engaging Service Users and Carers in: Research

Service users and carers can make a positive contribution to the research process in a number of different ways and be part of a research team. In recognition of the value they bring to the research agenda RSVP (Research Support Volunteer Programme) was developed.

What is RSVP?

RSVP was established in July 2012 to provide an opportunity to interested members of the community to contribute to research in health, social care and life sciences.

What does RSVP aim to achieve?

RSVP contributes to research in a meaningful, engaged and participatory way. Individuals provide their viewpoints, experience and skills on their experiences of health and social care and/or their health condition. A similar research programme for children and young adults will be launched in 2015. ([flyer link](#))

Who are the members of RSVP?

Members of RSVP come from a variety of backgrounds, occupations, experiences and viewpoints. However, they have one main goal that unites them – “Making an impact via research”.

What impact can RSVP have?

All contributions have a direct impact on the research being undertaken. Individuals provide a real-lived insight and greater depth of knowledge to the researcher, that without the participants’ feedback, they may never have known. ([Role Descriptor link](#))

How can individuals get engaged, get involved and get participating?

As a Researcher

As a Member/Participant

What type of research activities happen?

- Submit an **EXPRESSION OF INTEREST** to the Faculty Research Support Office, elaine.cartmill@coventry.ac.uk and an engagement advisory sheet will be supplied for perusal.
- **PRESENT** your ideas to the group. Click here for template ([PP template](#)).
 - Be invited to the RSVP monthly meeting, or an ad-hoc meeting can be arranged, (time permitting).
 - Receive direct feedback from group (if it is a research design, focus group or usability test).
 - Receive consent to participate in one-to-one interviews, or other research activities.
 - Please note: You don't require ethics for this phase.
- **GET INVOLVED OR GET PARTICIPATION.** This may involve one-to-one interviews or other research activities. Researchers can arrange a date and time directly with participants, providing further information. It is highly likely that you will require ethics application dependent on the research activity. See ethics.hls@coventry.ac.uk

For more information about RSVP please contact: Elaine Cartmill Research Support Office, 024 7765 5831 e.cartmill@coventry.ac.uk

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What type of research activities happen?

The RSVP has a Committee and Co-Chairs, creating autonomy for the group. Members are involved in professional and personal training such as writing bids, facilitation, interviewing, ethics, data entry and assertiveness/advocacy. The group meet on a monthly basis. ([ToR link](#)) The group also has ‘satellite’ members i.e. participants interested in particular subjects but not constrained to attend every meeting.

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What type of research activities happen?

Members can:

- **ENGAGE** by representing RSVP in seminars, presentations and conferences (training on presentation skills is provided)
- **BE INVOLVED** by proof reading leaflets, informing research design, co-applicant on funding bids, facilitating groups, collecting data - carrying out interviews, entering data, transcribing data. Being part of a research team!
- **PARTICIPATE** in focus groups, interviews, usability tests such as websites, apps, equipment.

For more information about RSVP please contact: Elaine Cartmill Research Support Office, 024 7765 5831 e.cartmill@coventry.ac.uk

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Engaging Service Users and Carers in: Research

What support is there for researchers?

There are a number of research examples, and publications pertaining to the engagement of service users in research, the added value, quality and impact.

<http://www.invo.org.uk/resource-centre/examples/>

TIP Whilst RSVP are familiar with research terminology used by academia, it should be used as little as possible or explained in lay terms.

TIP Be on time, be concise, and be considerate of participants' requirements and knowledge...they are the experts in their experience.

TIP Feedback is very important. Every contribution should be valued. A thank-you email, update or a copy of the findings are always appreciated.

How can I ensure Success?: To be successful you will need to consider:

Pre-Meetings

On the Day

Post-meetings

Useful Links

- No pre-judgements - members have a wealth of experience, knowledge, and are experts in their own experiences and conditions.
- Ensure you have clear aims and purpose - is it Participation, Engagement or Involvement you require?
- Regardless of whether its Participation, Engagement or Involvement, all should be meaningful and not tokenistic.

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- Be on time, be prepared, and make time for questions and answers.
- Be concise with your summary and presentations.
- Be clear about what is expected, how much time of involvement is needed and the costs involved, such as reimbursement, remuneration, etc.
- Ensure that identities are protected and in-confidence information is withheld.

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- Communicate with members promptly after meeting and keep them involved throughout.
- If there is nothing to report then please communicate this.
- Please reimburse and remunerate promptly
- Ensure that you give a point of contact for queries on their involvement or participation.
- Ensure that your provide feedback to members on the findings and the final report.

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- <https://ethics.coventry.ac.uk> :This provides guidelines on CU Ethics and Governance
- www.peopleinresearch.org :This provides examples of involvement in research
- <http://www.invo.org.uk/> :This provides best practice and guidance to support public involvement in research

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Engaging Service Users and Carers in: Selection and Recruitment

There are many ways that service users and carers can be involved in the recruitment and selection of students and academic posts. This varies from being on an interview panel, observing group activities, multiple-mini interviews and developing interview questions/ scenarios . Each course team will have their own preferred method.

Values Based Recruitment is a key priority for the NHS and for Higher Education. Values Based Recruitment aims to ensure that students are recruited for the values that are aligned to the NHS Constitution.

[Link to Higher Education England \(HEE\) Values Based Recruitment Framework](http://hee.nhs.uk/wp-content/blogs.dir/321/files/2014/10/VBR-Framework.pdf)
<http://hee.nhs.uk/wp-content/blogs.dir/321/files/2014/10/VBR-Framework.pdf>

Whatever methods are used there are 4 keys issues to consider:

Click below to find out more

Preparation

Preparation Tips

On the Day

Feedback and Evaluation

Service users and carers will require:

- An introduction and induction to Values Based Recruitment
- Clear information about the role that is being selected or recruited
- Clear information about their role and what is expected
- Guidance as to what questions can be asked and what questions can't be asked
- Clear information about the format of the day: arrival times, meeting place, expected time to finish
- Interview dates to be sent out beforehand in a timely manner so individuals are clear when they are required.
- A visitor car parking permit requested if this is needed
- Someone to meet and accompany them to the allocated room on the day

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
Assessment	Curriculum Development/Reviews	Research	● Selection and Recruitment	Teaching and Learning		



Engaging Service Users and Carers in: Selection and Recruitment

There are many ways that service users and carers can be involved in the recruitment and selection of students and academic posts. This varies from being on an interview panel, observing group activities, multiple-mini interviews and developing interview questions/ scenarios . Each course team will have their own preferred method.

Values Based Recruitment is a key priority for the NHS and for Higher Education. Values Based Recruitment aims to ensure that students are recruited for the values that are aligned to the NHS Constitution.

Link to Higher Education England (HEE) Values Based Recruitment Framework <http://hee.nhs.uk/wp-content/blogs.dir/321/files/2014/10/VBR-Framework.pdf>

Whatever methods are used there are 4 keys issues to consider:

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Preparation

Preparation Tips

On the Day

Feedback and Evaluation

Preparation Tips:

TIP Having the opportunity to have a mock practice or observe the actual activity that they will be involved in on the day is good preparation for service users and carers and any other parties that will be involved

TIP HLS staff involved in recruitment and selection need to fully understand the role of service users and carers in the process

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Preparation

Preparation Tips

On the Day

Feedback and Evaluation

- Service users and carers may be a little anxious and arrive early on the day
- The person who meets and accompanies individuals to the room will need to be prepared to go over the process and answer any questions
- Ensure they are offered a refreshment and are informed of where the nearest toilet is located
- Ensure that the necessary forms are available and completed for remuneration and reimbursement

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Whatever methods are used there are 4 keys issues to consider:

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Preparation Tips

On the Day

Feedback and Evaluation

- It's ideal to receive immediate feedback and evaluation following the event from service users and carers involved in the event. If this is not possible make contact or arrange to meet up if necessary
- It's important that the service users and carers are given feedback and evaluation of their contribution to recruitment and selection processes
- All of this information can be used to learn lessons and help to inform future recruitment and selection activities

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Engaging Service Users and Carers in: Teaching and Learning

There are a number of different ways that service users and carers can contribute to teaching and learning. This can be through the development of teaching and learning materials such as: case studies, scenarios, podcasts and videos. Some course teams organise experience days, where service users and carers talk to students about their personal experiences of health and social care and students have the opportunity to ask questions.

Face to Face delivery of teaching and learning can occur in:

- Small and large groups
- Individual teaching
- Co-teaching with a lecturer
- Simulation and role-play activities

Click below to find out more

- Preparation**
- Preparation Tips
- On the Day
- Feedback and Evaluation

Service users and carers will require:

- An introduction to the topic and aim of the teaching and learning session
- To be involved in the planning of the teaching and learning activity
- Clear information about their role and what is expected
- Information about the student group and how many are expected for the activity
- Clear information about the format of the day: arrival times, meeting place, expected time to finish
- Dates to be sent out beforehand in a timely manner so individuals are clear when they are required
- Relevant hand-outs or PowerPoint slides emailed beforehand and available on the day
- A visitor car parking permit requested if this is needed
- Someone to meet and accompany them to the allocated room on the day
- A contact person to inform of any changes or issues that may arise on the day

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Preparation

Preparation Tips

On the Day

Feedback and Evaluation

TIP Student Preparation is an important aspect of service user and carer engagement. [Click here for student preparation checklist](#)

TIP It can be useful for the service users or carers to observe a teaching session prior to delivering their session

TIP Extra support and guidance may be required to help develop presentation skills

TIP If service users and carers are involved in the podcasts and videos ensure that permission is gained and it is disclosed how the material will be used

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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- Ensure they are offered a refreshment and are informed of where the nearest toilet is located
- It's important that you make time for a debrief following the teaching and learning session
- Ensure that the necessary forms are available and completed for remuneration and reimbursement

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Preparation

Preparation Tips

On the Day

Feedback and Evaluation

Feedback and evaluation is required from all parties: service users and carers, students and academic staff. It's ideal to receive immediate feedback and evaluation from service users and carers involved either in the development of materials or delivery of teaching and learning. If this is not possible make contact or arrange to meet up if necessary.

Feedback and Evaluation from students is important and is best completed at the end of the session.

TIP

Asking students to describe their initial thoughts and feelings on sticky notes at the end of the session can be a quick and good way to gather feedback and evaluation. This feedback and evaluation can be shared with the service user and carer and followed up with students at the next session

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
Learning Disability: Tips and Resources	Learning Disability	● Children and Young People	Children and Young People: Tips and Resources			

Engaging With Specific Groups: Children and Young People

Children and Young people have contact with Health and Social Care services and therefore are an important aspect of Service User and Carer Engagement. They can contribute and enhance health and social care courses which can complement their education and generate an interest in Health and Social Care. However, there are a number of considerations that need to be taken with this client group.

What do we mean by Children and Young People?

It's important that we define what we mean by Children and Young People. The UN Convention on the Rights of the Child states that a child is anyone up to 18 years of age.

Click the link below for more information
http://www.unicef.org/crc/files/Guiding_Principles.pdf

What do you need to consider?



Click on the checklist to find out more



Please read the latest policy on Children on University Premises

Where can we access Children and Young People?

To access children and young people you may need to target local schools, colleges, community groups, young carers and relevant clinical areas and let them know about the opportunities to work in partnership with the university.

[Click here](#) for more information



Due to educational responsibilities face to face presence may not always be possible for children and young people. There are alternatives to this; this could be in the form of developing resources such as case studies, podcasts and videos with children and young people that can be utilised in assessment, teaching and learning and selection and recruitment.



Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
Learning Disability: Tips and Resources	Learning Disability	Learning Disability	Children and Young People	Children and Young People: Tips and Resources		

Engaging With Specific Groups: Children and Young People

What about parents?

Parents may also want to have a role in ensuring that the voice of children and young people is included in health and social care courses. Their role as a parent and their perspective is also an important component of this.

- TIP** Be mindful of the environment that the children and young person will be in e.g mannequins might be perceived as scary to a young child.
- TIP** Be mindful of your responsibility in regards to safe-guarding. Ensure that you know who to contact if you need to raise an issue. [Click here](#) to access the safe-guarding policy
- TIP** Be creative in terms of the activity to ensure the engagement of children and young people

Top Tips for Engaging with Children and Young People

Top Tips

Resources 1

Resources 2

- TIP** It's important that Children and Young People's engagement does not negatively impact their education
- TIP** The child or young person requires permission from their parent or guardian and their contact details are required
- TIP** Ask the young person if they want their parent to be present, do not assume!!
- TIP** Children and Young people value having feedback about their contribution in a timely manner

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Top Tips for Engaging with Children and Young People

- Top Tips
- Resources 1**
- Resources 2

- **Coventry Health and Social Care Directory** has a section on community voluntary services for children and young people <http://www.vacoventry.org.uk/directory>
- **Health and Safety Executive**
This link provides guidance about the law and responsibilities when employing young people. It highlights important areas to be considered when children and young people are on university premises. <http://www.hse.gov.uk/pubns/indg364.pdf>
- **INVOLVE**
This link provides a number of examples of how children and young people are being involved and collaborating in research.
<http://www.invo.org.uk/?s=children+and+young+people>

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Top Tips for Engaging with Children and Young People

- Top Tips
- Resources 1
- Resources 2**

- **PEAR Guide**
A useful guide written by young people about how to support and involve them in research
http://www.ncb.org.uk/media/110695/pear_leaflet_final_lores2.pdf
- **Viper Guide** - [Click here](#) to access the Guide
A useful guide written by young disabled people about how to get them participating and involved.
- **Voices of Care**
This is a group that represents looked after children and young people organised by Coventry City Council. As well as making their views heard to the council about their experiences to improve services, they also contribute to educational activities, interview panels.
http://www.coventry.gov.uk/info/37/childrens_social_care/778/voices_of_care

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Engaging With Specific Groups: Learning Disability

Individuals with a Learning Disability are an integral aspect of service user engagement and make a positive contribution to educational and research activities. It is recommended that to engage with an individual with a Learning Disability that you will need to have some Learning Disability awareness.

What is a Learning Disability?

<https://www.mencap.org.uk/definition>

When working with individuals who have a Learning Disability there are a number of things that you need to consider:

- What specific role/activity do you want the individual to be involved in?
- What are your expectations of the person?
- How will you prepare them for the activity?

It is essential that this is clear for you and the individual with a Learning Disability.

Community Organisations

Many people with a Learning Disability attend community organisations; this is a good way to recruit individuals or groups as they will have:

- Established confidence and trust
- They enable people with a learning disability to have a voice
- They will have an in-depth understanding of their needs
- They can ensure a diversity of individuals

Others may live with parents who may be classed as a carer. Therefore it's important that you establish who is the best person to contact:

- The Individual?
- The Organisation?
- The Carer?



Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Engaging With Specific Groups: Learning Disability

When wanting to work with this client group you need to think about how you communicate and ensure that:

- You are understood
- They understand You

You may need to consider if there are any communication issues?

- Sensory?
- Speaking?

Will you require some support with this?

Mencap "[Getting it Right](#)" suggests :

- Pay attention to facial expressions.
- Notice gestures and body language.
- Try pointing to pictures.
- Keep information simple and brief
- Avoid using jargon

For more information [Click Here](#)

TIP

If you need to provide written information you may need to provide this in an accessible format and include:

- Pictures
- Symbols
- Big fonts

[Click here](#) to access a guide on making easy read information

Top Tips & Resources

Top Tips

Top Tips 2

Student Tips

Resources

TIP Develop sessions in collaboration with individuals with a learning disability

TIP You will need to think about accessibility very carefully as it is very important to this client group
Link to the accessibility checklist

TIP You need to be aware if there are physical care needs of the individual

TIP You may need to explain things a number of times, so give yourself enough time

TIP If you are unsure or require some support please ask

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Top Tips & Resources

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Resources



You may need to repeat information to help the person understand and to check their understanding



Give enough notice of the meeting, time to read or to gain support or ensure that you go through the information with them



Meet at a place that they are familiar with



Engage with a learning disability community organisation for strategies for communication with and guidance in the design of activities

Framework	Initial Engagement	Support for Service Users and Carers	Engaging Service Users and Carers	Engaging with Specific Groups	Top Tips for Service User and Carer Engagement	Useful Resources
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Top Tips & Resources

Top Tips

Top Tips 2

Student Tips

Resources

Student Preparation

Students will need to have some preparation before the involvement of individuals with a learning disability. [Link to student preparation checklist](#)



It's a good idea for students to do some pre-reading to gain some basic awareness of what a learning disability is



The session may not go as originally planned so some pre-warning of this to students would be useful



Encourage students to ask questions that are not the usual everyday questions to enable them to understand the level of ability of the individual and their communication needs

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Top Tips & Resources

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Grapevine is a community organisation in Coventry and Warwickshire that provides a number of services to individuals with a learning disability, their carer's and families. They have expanded this provision and also provide services to young undocumented migrants, 'Troubled Families', disabled people, vulnerable parents and local neighbourhoods. <http://www.grapevinecovandwarks.org/>

Learning Disability Made Clear

This is a useful education and training resource about Learning Disability designed for staff in health and social care settings.

<http://www.learningdisabilitymadeclear.nhs.uk/toolkit/3-learning-disability-made-clear-toolkit>

Mencap is a leading national charity that works with people with a learning disability to change laws, challenge prejudice and support them to live their lives as they choose. The website has a number of resources covering all aspects of learning disability

<https://www.mencap.org.uk/>



Service User and Carer Engagement

TOP TIPS

Its important that Service Users and Carers feel

**WELCOMED,
SAFE, INFORMED
and RESPECTED**

Be mindful of :

**ACADEMIC LANGUAGE
JARGON
and ACRONYMS**

Try to work with a variety of Service Users and Carers and

“REFRESH”
their contribution
and activities

Be
“TRANSPARENT”
with Service Users and Carers about what you can and can't do

Be mindful that it takes
TIME to work
EFFECTIVELY
with Service Users and Carers

If you are
“UNSURE”
where to start with Service User and Carer Engagement or what you need to do then please ask

Useful Resources

for Service User and Carer Engagement



The Eight Principles for involving service users and carers

This paper outlines the minimum standards for involving service users and carers in your work and what this is required to achieve the standards. It outlines a benchmark for all to work to and achieve.

Social Care Institute for Excellence

This website has a number of resources that relate to service user and carer engagement in education and in practice. Although targeted at Social work and social care the content is applicable to areas of health too. You may need to register to access some documents. Registration is free. Suggestions of keywords to search: service user and carer involvement, service user and carer participation; co-production.

NHS Involvement

This is a Patient and Public Participation Programme funded by the NHS. It has a vast amount of resources which gives guidance and tools to support patient and public participation in the NHS. Its free to register.

INVOLVE

INVOLVE are funded by the National Institute for Health Research (NIHR). The website has a number of useful publications and guidance for patient and public involvement in the NHS, public health and social care research.

The Plain English Summary

This is provided by INVOLVE who support patient and public involvement in the NHS, public health and social care research. The summary gives useful pointers and examples when developing materials for a non-academic audience.

Beresford, P (2013) Beyond the usual suspects, towards inclusive user involvement. Shaping Our Lives

This paper is based on a research project supported by the Department of Health. It outlines the barriers for service user involvement for particular individuals and groups and provides tips and practical strategies for overcoming them.

Health and Care Professions Council (HCPC)

This is the seminar presentation by the HCPC which outlines the key issues that need to be considered in the new standard of education and training which states that: "Service users and carers must be involved in the programme. Page 29 contains an activity using case scenarios to create discussion and thought about how to involve service users and carers and some of the issues that surround this. The case scenarios are below.

[HCPC Seminar](#)

[Case Study \(SU&C\) 1](#)

[Case Study \(SU&C\) 2](#)

[Case Study \(SU&C\) 3](#)

[Case Study \(SU&C\) 4](#)

The service user and carer toolkit

This is a resource for staff that work in Health and Social Care and Social Work in higher education. There are 10 sections which aim to give guidance and support to staff when working with service users and carers in higher education. The toolkit provides context to each section, practical advice, case studies and references.