Equal Partners in Care (EPiC): Practice guidance for working with carers and young carers
Sharing practice

One of the most effective ways to bring about a change in working culture is to share good practice and learn from what other people are doing. We are very grateful to those who have shared examples from their practice and case studies of the carers and young carers they work with. We have linked each of these examples to one or more of the outcomes in the core principles as well as guidance on planning and delivering workforce education and learning on carers and young carers. We hope you find these inspiring and useful and welcome any examples you may have to share of how you have used the core principles in your practice.

Go to [www.knowledge.scot.nhs.uk/equalpartnersincare](http://www.knowledge.scot.nhs.uk/equalpartnersincare) for a full version of the core principles, as well as learning resources to support your practice in relation to carers and young carers or to share resources or practice examples of your own.

About the EPiC project

Equal Partners in Care (EPiC) is a joint project between NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to implement the workforce education and learning elements of Caring Together 2010-15, the Carers Strategy for Scotland. We aim to support workers from health, social services and other sectors to work in partnership with carers and young carers, and to achieve better outcomes for all involved in the caring relationship. We will do this by providing learning resources to help best practice become universal practice.
Early identification can mean that carers are able to continue caring for longer, with better outcomes for them and the person they care for. Sometimes carers are referred to as ‘hidden’ but carers to not usually conceal themselves. If we pay attention, we will see them right next to the person they care for, such as beside their hospital bed, answering the door when you visit the person they care for, collecting their prescription or bringing them to the GP surgery.

Example: The Moffat Project
A key time to identify carers is when the person they care for is admitted to or discharged from hospital. The Moffat Project carried out a pilot of partnership working between acute hospitals and carers centres affiliated to the Princess Royal Trust for Carers. The project found that this raised awareness of ward staff and increased the identification of carers particularly during admission and discharge.

Link to Moffat report

Example: Carer awareness training
Carer awareness training can dramatically increase carer identification. A joint project between NHS Tayside and Dundee Carers Centre sought to implement some of the recommendations of the Moffat report. As part of the project, a simple referral pathway was agreed, referral postcards were distributed and one-hour carer awareness sessions were delivered to more than 100 ward staff. The number of carers identified in hospital and referred to carers centres in Tayside increased by 720% in two years.

Example: Carers & Young Carers: GP resource
The Royal College of General Practitioners (RCGP) and the Carers Trust in Scotland have developed a resource to support GPs in identifying carers and young carers. GPs and practice staff can play a crucial role in identifying and supporting unpaid carers and young carers. The resource gives practical guidance on issues such as confidentiality, involving carers in decision-making, and signposting to relevant support. The resource was developed in partnership with P3 – the RCGP’s patient and carers group.

Link to RCGP resource

“Previously my main priority was the patient and now I have completed this course I will make sure the carer has more of a priority and involvement in the patient’s care” Nurse
Carers are providers of care and may need resources to enable them to continue caring. Caring can have a significant impact on the carer’s health and quality of life. These resources can include information, emotional support, benefits advice, short breaks (respite care), training and quality services for the person they care for.

Carers assessments (also called Carer Support Plans) are one way for carers to access the support they need to continue caring. Carers have the right to request an assessment and local authorities have a duty to inform carers of this right. Every worker should be able to signpost carers to access an assessment.

Guidance: Carers Assessments
The Scottish Government is producing a practice guide to support workers to improve the quality and uptake of carers assessments. It is intended as a practical, clear, easy-to-use guide for anyone who has a role in carrying out assessments. Each chapter has an example to illustrate good practice in carers assessments. It also gives an opportunity to reflect on your values, knowledge and skills in working with carers and has links to useful resources and tools. You can download this guide here when it is available.

Guidance: Confidentiality
It can be difficult to balance the right to confidentiality with the carer’s need for information. Any decisions made about the person’s treatment and care plan will have an impact on the carer. As with other partners involved in the care, carers need information in order to carry out their role. At the same time, the person has a right to confidentiality. NHS Lothian has produced guidance on Sharing Information with Carers and Families.

Guidance: Talking Points
Personal outcomes involve focusing on what matters to the carer or person who uses services, and what they want to change. An outcomes approach puts the emphasis on what can make a positive difference. It also enables carers to share in the decision making about what services are provided. An example of a tool for developing this approach is Talking Points. The Talking Points Personal Outcomes Approach has been developed by the Joint Improvement Team (JIT) to support a focus on the outcomes important to people using social care services and their carers. The key objective of this approach is to obtain a holistic picture of the person’s life and the goals they want to achieve and to move away from the more limited exercise of matching individual needs or problems to a limited range of services.

Example: Carers Together

Carers Together in North Lanarkshire is working with Carers Scotland and the Scottish Personal Assistant Employer’s Network (SPAEN) to deliver training to carers on self-directed support. They also provide ongoing support to carers accessing an individual budget either for themselves or for the people they care for. Carers are better informed of their choices around self-directed support and the options available to them. This has also had a positive impact for workers at SPAEN who are more aware of carers’ needs and will ensure that their services are responsive to these. They will use a person-centred approach with people using services.

Example: Centre for Brain Injury Rehabilitation

The carers group at the Centre for Brain Injury Rehabilitation (CBIR) in Dundee is run by the clinical neuropsychology department with family members of patients using the centre. Members identified 5:30pm as a good time for the group to meet as it allows people to finish work and coincides with the centre’s evening meal time so they are not missing out on important visiting time. A person-centred approach was used to ensure that the group meets the needs of those attending. The aim of the group is to ensure carers are informed about brain injury and the recovery process, giving them time to discuss questions with supportive peers and a psychologist. The topics are chosen in advance by group members.

Guidance:

Working with Children and Families Affected by Substance Misuse

Getting our Priorities Right: Good Practice Guidance for Working with Children and Families Affected by Substance Misuse (2003) is for those working with children and families affected by drug and alcohol misuse. It focuses on the impact on carers and families, and involving them in planning long-term support for the people they care for. There is a chapter on Getting it Right for Children in Substance Misuse Families which specifically refers to young carers. Services should be alert to the possibility of young people taking on inappropriate levels of responsibility when parents or other family members are affected by substance misuse.

Link to Getting Our Priorities Right

Guidance:

Using evidence to inform how we support families with disabilities

About Families is a partnership between the Centre for Research on Families and Relationships, Parenting across Scotland, and Capability Scotland. The project aims to support voluntary and statutory sector organisations to develop their services to meet the changing needs of parents and families, including those with disabilities. About Families launched ‘Together and Apart: Using evidence to inform how we support families with disabilities’ in 2011. This evidence report explores how parents can be supported to maintain healthy relationships and cope with relationship difficulties.
Guidance: Supporting relatives and informal carers – top tips for mental health workers
These top tip cards have been produced in partnership by NHS Education for Scotland and Support in Mind Scotland. The tips are to help busy workers remember the importance of carers in supporting people’s recovery. Workers are only visitors to someone’s life, relatives and carers are there all the time. You can use these tips to help make sure carers get the support and information they need. The tips come from carers of people with mental health problems who were asked questions about their experiences with mental health services in a survey carried out by Support in Mind Scotland. There are tips about confidentiality and a reminder that giving information is not a one-off exercise, and even experienced carers may need information in an understandable form, especially at times of stress.

Link to Top Tips

Guidance: Triangle of Care Guide to Best Practice in Mental Health Care
Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care (2010) reflects years of research into the information and support that mental health carers need from service providers. Carers are often the only constant in the mental health journey of the person they care for. Triangle of Care helps mental health workers to recognise the support that carers give and acknowledge them as partners in care.

The guide has been very well received within England, with 32 Mental Health Trusts expected to complete a Triangle of Care self-assessment by April 2013. In Scotland, we are still at an early stage of adapting and implementing Triangle of Care but the initiative has the support of the Scottish Government and several health boards. The Princess Royal Trust for Carers (Carers Trust) is leading the promotion of Triangle of Care to health boards, carer organisations and carers in Scotland.

Link to Triangle of Care
Short breaks or respite care means a carer and the person they care for are supported to have a break from their caring situation. This is an essential part of the support that families and carers need to continue caring. Short breaks should deliver positive outcomes for all involved in the caring relationship. A short break can mean the carer has a break away from the person they care for, the person has a break away from home, or they are supported to take a break together.

Managing conflict – sometimes the needs of the carer and the needs of the person they care for can come into conflict. A carer may need a break from their caring role but the person they care for may not wish to engage with services and have strangers looking after them. This can create a crisis situation if the carers ‘burns out’ and is unable to continue caring, putting the person they care for in the position of having to enter residential care they didn’t choose. It can be difficult to manage a situation where needs appear to conflict and it’s important to address the issue sensitively. If it is the person’s choice to be cared for by one person, then the carer will need regular breaks to make sure this is sustainable. In many cases, the initial distrust of ‘strangers’ can be overcome if the care provided focuses on the person’s needs and outcomes and supports them to build a relationship with the new provider. A short break for the carer can become something that the person they care for enjoys too. Having this conversation can be tricky, but there are tools available to help you focus on outcomes.

Guidance: Talking Points
Personal outcomes involve focusing on what matters to the carer or person who uses services, and what they want to change. An outcomes approach puts the emphasis on what can make a positive difference. It also enables carers to share in the decision making about what services are provided. An example of a tool for developing this approach is Talking Points. The Talking Points Personal Outcomes Approach has been developed by the Joint Improvement Team (JIT) to support a focus on the outcomes important to people using social care services and their carers. The key objective of this approach is to obtain a holistic picture of the person’s life and the goals they want to achieve and to move away from the more limited exercise of matching individual needs or problems to a limited range of services.

Link to:
Example: Short Break Planner
Shared Care Scotland has produced a Short Break Planner to help carers, the people they care for, and their care managers, to plan short breaks which meet the needs of all involved. This resource is for people who already receive short breaks and want to make the most of them, as well as people who are trying to get these services. The information, advice and experiences of others can support them to get the service they need. Care managers can use the resource to get a better idea of what short breaks will best meet the needs of carers and the people they care for. Link to Short Break Planner.

Example: Shared Lives
Shared Lives is a model of care that offers either permanent support or regular short breaks in the home of a local family, where the person is fully involved in family life. Shared Lives services are about families sharing their lives, home, interests, experience and skills with other people who need support. The person is welcomed as a member of the family of a Shared Lives carer who is checked and approved, trained and monitored by the scheme. It is an alternative to residential respite care. Shared Lives schemes in Aberdeenshire and Edinburgh support people with a learning disability but increasingly local authorities are looking at using them for different groups, such as people with dementia. Shared Lives focuses on what the person wants and needs to live their life and fulfil their ambitions. It is highly personalised and is delivered by the community in the community. View the Shared Lives Plus video.

Example: Dementia Café
The Dementia Café in Motherwell is a partnership project between NHS Lanarkshire, North Lanarkshire Carers Together and Motherwell community mental health team to support carers looking after someone with dementia or memory loss. Carers were consulted to identify what service would best meet their needs. It was clear that carers wanted to attend a group along with the person they cared for to reduce isolation, provide access to information and services, and an opportunity to speak to other carers in an environment that was supportive and inclusive. Carers have a regular place to go with the person they care for and have somewhere to meet other carers in a similar situation. Many carers state that this is a break for them as well as helping them to access services. The dementia café team includes specialist doctors, memory service nurses, occupational therapists,Equals Advocacy Project, and Alzheimer’s Scotland. Young carers were also involved as volunteers at the café and this helped to develop connections between the generations. The venue Motherwell football stadium appeals to all ages as it is familiar to locals and a trigger for good memories. The dementia café won the Best Dementia Friendly Community Initiative at the Scottish Dementia Awards in 2012.

By providing Carers with a much needed breaks via this fund VSA Carers Services in Aberdeen aimed to ensure that:

- Carers and those they care for will have improved physical, mental and emotional wellbeing
- Carers will be better able to live a life outside of caring
- Carers will be better able to sustain their caring role
- Hard to reach carers will be better supported in accessing short breaks and respite care

Adult carers were partners in the project as they were included on the short breaks panel which made the decision on each application to the fund.

We wanted this project to be inclusive of carers and to reflect their needs.

The project was funded by Shared Care Scotland and the Time to Live Fund.

This project enabled a large number of carers to receive a much needed break. Feedback from the carers who received funding was sought before and after their break:

“This short break really helped to rescue me from stress and exhaustion. Now 72, I do suffer more physically and emotionally with the struggle to obtain better services for my son…”

Older parent carer
Carers may experience disadvantage as a result of their caring role, which can have an impact on their health, finances, work and education. Some carers may have more difficulty accessing support from services than others due to age, disability, sexuality, ethnicity or other issues. Carers from minority ethnic communities may face barriers relating to language, communication and culture. Bear in mind that people don’t fit neatly into categories, so an older person may also be an LGBT carer and have health needs themselves. We should always be aware of equality and diversity issues. This is sometimes called cultural competence.

**Guidance: On the Margins audit tool**

MECOPP has developed an audit tool called On the Margins which can help you assess your service and improve your understanding of ‘cultural competence’. The toolkit is aimed at services working with carers from minority ethnic communities (or BME), but it can be easily adapted for use with other groups, such as older people or disabled people. You can use the toolkit to:

- Support and feed into existing auditing and improvement mechanisms,
- Identify actions which can be fed into existing Service Plans and strategy reviews;
- Support outcome measurement frameworks
- Inform Equality Impact Assessments

You can download the toolkit from [here](#).

**Guidance: Carers Rights Charter**

The Minority Ethnic Carers of Older People Project (MECOPP) is developing a carers rights charter. You can download this from the [EPIC portal](#) when available.

**Example:**

**Dumfries and Galloway Carers Strategy LGBT Charter Mark Project**

The Dumfries and Galloway Joint Carers Strategy has as one of its strategic objectives: “all carers have access to support, advice and services when they need it and in working towards this, have an ambition that all carers regardless of age, race, disability, sexual orientation, gender or religion will feel supported across Dumfries and Galloway and enabled to continue in their caring role.” It was recognised that of all the groups with protected
characteristics, the needs of LGBT carers were least understood by decision makers and frontline workers, and that work had to be undertaken with key staff / agencies.

At present, we are at the very beginning stages of the project, and have had a launch event in February 2013. Three carers took part in the event to share their stories. In addition, a film called Gen Silent was screened which highlighted the specific issues for LGBT older people, both being looked after at home and entering the care home sector. These carers plus a young carer will share their stories again in the creation of a DVD which can be used in training in the future, and where appropriate, carers will be asked to co-deliver training sessions with LGBT Centre staff. Other plans include supporting carers organisations to achieve the LGBT Charter Mark award, workforce education and learning to make staff more ‘LGBT aware’, and training for LGBT Centre staff to be more ‘carer aware’.

This project is being carried out in partnership between the LGBT Centre and NHS Dumfries and Galloway and is funded under the Joint Carers Strategy. Regular partnership meetings will take place throughout the duration of the project which will ensure that the work remains embedded in local priorities.

Guidance: Care About Rights

This resource, produced by the Scottish Human Rights Commission, is intended to allow everybody who is involved in care and other services for older people to better understand and use a human rights based approach to care and support.

The pack is directed at three main audiences:

• people who use care and support services, their carers and families.
• workers in the care sector, for example in care homes, care at home or housing support services. This may include owners, managers, care workers and other staff.
• people whose job involves policy making for the care sector, commissioning or regulating care services.

The resource can be used for workforce education and learning and includes film case studies to explore real life and potential situations to help you work through the issues in practice, and apply what you have learnt. The issues explored include situations when the rights of the person receiving care and their carer come into conflict, experiences of people from minority ethnic communities and same sex partners.

There is also a section for people who use services, families and carers.

Link to Care About Rights
Engaging carers and the people who use services in planning and shaping them can result in better services and better outcomes for all involved. This involvement should be meaningful and not tokenistic.

To help services improve the way they engage with carers, the Coalition of Carers in Scotland is developing Best Practice Standards. You will be able to download them from the EPiC portal when available.

Example: Dumfries and Galloway carers strategy
In Dumfries and Galloway, a carers reference group (CRG) was set up to inform the development of the Joint Carers Strategy 2012-17. There is also a ‘virtual CRG’ for carers who cannot take time away from their caring role to attend meetings. The strategy was developed in partnership with carers, carers centres and a Carers Interest Network of managers and project leaders of carers’ services. The CRG is now involved in developing and delivering the Carer Aware workforce education and learning programme.

Example: Golden Rules for engaging young carers
The Golden Rules were developed by a group of young carers who had attended a session with MSPs where they felt they had not been listened to. Subsequently, the Children’s Commissioner invited them to educate decision makers about how to engage with young people. The young carers created a set of ‘Golden Rules’ and presented them at an event called ‘Am I Getting it Right?’ in November 2012. See the Golden Rules on page 13.
The Golden Rules for Engaging Young Carers ...

**Do’s**
- Stay focused on the specific subject
- Answer the questions directly to the young people
- Engage informally
- Feel free to ask questions to the YOUNG PEOPLE!!!
- Be organised and actually know WHY you are there
- You need to be involved with the young people
- Be casual!!!
- Be interested
- Be creative
- Listen
- Be polite
- Take notes
- Be prepared
- Be interactive
- Take us seriously

**Don’ts**
- Don’t be patronising
- Don’t argue
- Don’t dodge questions
- Don’t answer your phone
- Don’t be boring
- Don’t act better than us
- Don’t act like you know it all
- Don’t judge a book by its cover
- Don’t undermine the young carers
- Don’t compare your life to young carers
- Don’t interrupt
- Don’t walk out on young person speaking because it’s rude!
- Don’t judge all young people in society today – we aren’t all neds!
- Don’t make excuses in general – if you don’t know the answer just say
- Don’t think it’s a walk in the park, it takes time my friend.
Example: Glasgow Appoints New and Independent Carers’ Champion

Glasgow City Council appointed former councillor Dr Christopher Mason MBE as the city’s new, independent Carers’ Champion - the first in Scotland – in December 2012.

In his new role as Carers’ Champion, Christopher will be expected to listen to carers, understand their needs, and ensure that their views are properly heard within the council.

He will also be expected to undertake a series of visits and meetings with the carer community in Glasgow, which is estimated to number more than 55,000 people, and be tasked with playing a key role in establishing a Carers’ Reference Group, which will bring together representation from established carer groups, networks and forums from across Glasgow under one umbrella.

Christopher was identified for the role in large part due to his long standing commitment to developing support services for people with autism in Glasgow. He was confirmed in the position following a meeting of the council’s Executive Committee, which gave cross party support to the role of Carers’ Champion.

Example: www.stroke4carers.org

Carers of people who have had a stroke were an integral part of the steering group for this project to develop a free website for unpaid stroke carers. Two carers came to each meeting with a third attending via video conference from Wick. 55 other carers took part in consultations by focus groups, face-to-face, e-mail or telephone to discuss and lead the content of the website. CHSS support nurses across the country asked carers what their needs were. Other partners included NHS, carer organisations, University of Edinburgh, Big Lottery Fund Scotland and the National Advisory Committee of Stroke. The aim of the website is to increase carers’ knowledge and offer advice, support and information about stroke whenever it is needed and at whatever stage in the person’s recovery. The website offers help for carers to access information and services for themselves. It also features stroke training and awareness resources. Health and social care workers are using the website to give carers and families more information and as a training resource, especially using video clips as examples for staff and carers.
The Carers Strategy is quite clear that carers are equal partners in care. That means that they have the right to be involved and to choose their level of involvement. This outcome is linked to most of the others and can be seen as critical to ensuring that carers have the recognition they deserve for their knowledge, insight and experience in caring.

A young person may also be the main carer and have valuable knowledge of the condition of the person they care for. Young carers often report that they are ignored by the health and social workers involved with the person they care for. They may not be asked to contribute to care planning and decisions.

Example: Young Carer’s Authorisation Card
Fife Council, NHS Fife and Fife Young Carers Project are working together to pilot a Young Carer’s Authorisation Card. This will help workers to identify young carers and involve them in discussions and decisions about the person they care for. It will facilitate information sharing and will help ensure that care plans will not rely on the young person having an inappropriate caring role. You can see details of this scheme on the EPIC portal.

Example: Tayside Forensic Voices
Tayside Forensic Voices is an independent charity run by carers for the benefit of carers and families of patients and former patients of the forensic unit at Murray Royal. The group enjoys close links with workers in the unit, enabling carers and staff to work together to resolve problems and improve services. Doctors and nurses support the group and often attend meetings and events. This gives them a real insight into carers’ needs and concerns, and they work together with carers to resolve problems and improve services. Carers are considered equal partners in the planning, design and operation of forensic mental health services at Murray Royal. They are encouraged to propose new ways of working and have regular meetings with consultants, nurses, OTs and medical managers. Workers benefit from having a supportive (and on occasion critical) group that can speak for carers and enter into constructive dialogue with staff. Carers benefit from knowing that their needs and concerns will be listened to and, in most cases, acted on. The forensic service in Tayside benefits from having a strong and vocal champion for service improvements.

VSA Carers Service involved adult carers as partners in this project as they were included on the short breaks panel which made the decision on each application to the fund. We wanted this project to be inclusive of carers and to reflect their needs. We planned to include carers of different ages and who are caring for people with different conditions as well as representatives from social care, health and other organisations.

We asked carers on the panel to give us direct feedback on their experience of working with us after each session and at the end of the project. We sought to respond to the needs identified as the project progressed. All of the staff working alongside carers on the panel gained a valuable insight into their caring experiences. The carers who worked in partnership with us gained new confidence, helped other carers and made a valuable contribution towards the project’s overall success. VSA will continue to work in partnership with carers in the development of all aspects of its work.
Workforce education and learning

The EPIC portal [www.knowledge.scot.nhs.uk/equalpartnersincare](http://www.knowledge.scot.nhs.uk/equalpartnersincare) hosts a number of online learning resources but people learn in different ways and many workers prefer face to face training to online learning. If you have a role in planning and delivering workforce education and learning, you can use the EPIC principles to plan learning outcomes (you can download these from the portal). We have provided some guidance below on good practice in involving carers in workforce education and learning and how you can use the principles at different stages of the process of planning, delivering and evaluating training. We also link to some practice examples of carer awareness and other training currently being delivered across Scotland.

If you are planning training on carers and young carers, assess the need for training and link it to the different levels of the principles. For example, do you need to deliver carer awareness (level 1) training to a large number of workers? Some health boards and local authorities have made this a mandatory part of induction training. Others have included a carer awareness module in order training being delivered such as dementia or adult and child protection.

Involving carers:

As far as possible, include carers in planning training, as they are well placed to identify what workers need to know and be able to do. If you have a carers reference group you can involve them as partners in the process or you could invite input from a local carers centre. Carers can also be involved in the delivery of the training, in planning content or by including carers’ stories. The carer’s voice is an important element of training to help the reality of the caring experience come alive for learners. This can be done either in person or with video carer stories. To empower the carer before telling their story, some providers offer training in public speaking and confidence building. We have some examples of innovative approaches which involve learners spending time with the carer and the person they care for at home as part of their training.

Planning learning outcomes:

You can use the principles to plan the learning outcomes for the training and to ensure the content is appropriate to the level. You can link this to the job role, the level of engagement with carers and young carers, or the leadership demonstrated in relation to carers. For example, a receptionist or care at home worker may begin with level 1 and determine that they have regular engagement with carers. They can choose to enhance their practice by accessing level 2 training. As their confidence builds, they may then decide to take on a leadership role, for example as a carers lead or ambassador within their workplace, and may be interested in level 3 training. If you are planning training in partnership with carers, you may find level 3 relevant to your role.
The levels are designed to work cumulatively, so every worker should have level 1, then proceed through levels 2 and 3. Some learners may find they are at level 1 for some areas of their work, level 2 for others and level three for yet more. This can be useful for evidencing personal and professional development in line with their career frameworks (such as NHS Knowledge and Skills Framework and the Continuous Learning Framework for social services).

**Measuring impact:**
You can also use the principles to measure the impact of the training. For example, workers feel more confident identifying carers. Consider taking a baseline before the training is delivered and then monitor any increase in referrals for carer support or uptake of carers assessments.

When you are planning your learning outcomes, think about how you will measure them. Evaluation is more effective when it is integral to the process and not just a questionnaire at the end of the session. Use creative approaches to encourage participation and give quantitative (such as a scale of increased confidence) and qualitative results (such as quotes).

Determine how to capture carers’ views on the impact of the training. This can be formal (a carers reference group) or informal feedback (with carers of people using your service or local carers’ groups). It can be difficult to link carers’ outcomes to specific training so this is best done in the context of longer term service improvement.

Link to [Evaluation Support Scotland](#)

Evaluation Support Scotland (ESS) works with voluntary organisations and funders so that they can measure and report on their impact. Their website gives access to evaluation tools and support.

**Tips for developing e-learning**
- Clear consents from participating carers for digital stories
- Intellectual property rights
- Plan project and keep all informed
- Have clarity of roles in the partnership
- Be willing to adapt and use action learning as the project develops
- Look to potential future use during the development stage, such as other health boards using the modules
- Consider your target audience carefully – generic or specific content
- Consider the use of learning interactions for key learning points and to enhance the learner experience (if funding is available)
- Add formative questions at the end of each section to check that the learner has understood the content
- Before the module is finalised it should be tested by the SME and a small group of potential users for constructive feedback
- Module content should be reviewed on a regular basis (every 2 years at least), or more frequently depending on legislation changes or content subject. SMEs should sign up to this and inform you of any updates required
Accessibility issues:

- Keep the text plain and simple – don’t use jargon
- Use dark text on a light background
- Try not to use red and green together (will cause problems if reader is colour-blind)
- Only use capital letters and italics where they are really needed – avoid acronyms and abbreviations
- Use minimum punctuation
- Use paragraphs, bullet points and images to break up solid text
- Use first tense ‘you should...’ rather than ‘all staff should...’
- Check copyright on all images and add meaningful Alt-Text (for screen readers)
- Do not use flickering or flashing images as they distract from learning (may trigger fits in some users)

Example: Carer Aware training programme, Dumfries & Galloway

The carers strategy team of Dumfries & Galloway has developed a five tier carer aware training programme which is being rolled out across the region to a wide range of partners. Training will be delivered to local authority and NHS workers as part of induction. Additional levels will attract role specific interest and partners can also access the training. The elected members of D&G council have agreed to undertake the training online and identify specific areas of interest for further training. This is the first time this approach has been used in Scotland. Carers have been involved in the planning and delivery of training, initially as part of the carers reference group for the Joint Carers Strategy 2012-17. The training was developed in consultation with carers, carers services and national partners. As the volume of training to be delivered will be substantial, carers can’t be expected to attend each training session so a DVD is being developed to ensure carers’ experiences are at the heart of each session.

Example: Child and family services communication course, Tayside

This course was initially focused on child and family complex needs workers but has now been extended to other groups of staff working with children and families in NHS Tayside and partner organisations. It was developed in response to a review of services where parents said that difficult news was not always shared in a sensitive manner by workers. Parents who had personal experience of child and family services were asked to be involved in planning the training. They identified different situations were difficult news had been shared badly or well and provided stories of their caring journey. Parents from the Parent-to-Parent organisation volunteered to do role play as part of the training to provide more realistic feedback.

“Having real mums in really helped the role play scenarios”
Example: Carer Champion training programme, Lanarkshire
The aim of this training is to establish carer champions in acute and community health settings (including AHPs and GPs) and empower them to support, refer and signpost carers to appropriate support, and cascade this information to their colleagues. The programme was developed as result of feedback from previous carer awareness sessions delivered by the NHS Lanarkshire carer support team. Many workers in acute settings indicated that it was a challenge to be released to attend an awareness session. They felt more in-depth discussion was needed than was possible within the time available. Workers felt that the title of champion was readily recognised and the associated role understood. The carer champion training programme was planned in partnership with NHS Lanarkshire, North and South Lanarkshire councils, Princess Royal Trust Lanarkshire Carers Centre, North Lanarkshire Carers Together, South Lanarkshire Carers Together and Action for Children’s North Lanarkshire young carers project. The programme day is flexible and the training is delivered by the carer support team, senior nursing staff and representatives from a number of carer organisations. Carers have provided first-hand accounts of their caring experiences and a DVD developed by carers from minority groups has been used to focus on key issues affecting carers. The programme will continue to be developed and a database of the carer champions will enable contact beyond the initial training and provide further support if needed. Workers who have completed the training report that they have used available opportunities to cascade their knowledge of carers to their colleagues. Some of the carer organisations have reported an increase in referrals. Bank staffing is used to provide frontline cover to enable workers to attend.

Example: Carer awareness training, Highland
This training is for hospital and community workers, both nursing and AHPs, as well as community social workers. The training was planned in partnership with the local carers centre to identify content and delivery method. The session follows the model of the Highland Carers Strategy priorities for supporting carers. The two-hour session is designed to be as active as possible using a variety of different learning methods to facilitate discussion and learning about carers. Essential elements of the course include:

- carer involvement and storytelling
- tailored to each group
- integrated evaluation
- course materials

Where possible carers have been involved at all stages in the design and delivery of the course. The course was developed following the Coalition of Carers in Scotland good practice in carer awareness training guidance. Carers were involved in writing material, in developing many of the exercises and in delivering training sessions. Carers talk from their experience, about what their caring role involves and what has worked well for them in terms of support. There are DVD stories from young carers. Carers were invited to participate in ‘seven tips for building confidence’ and ‘telling my carer story’ courses before becoming involved in delivering training. Carers have found taking part in the training challenging but rewarding. In general, workers felt that the course had made a real difference to their attitude. Participants are also asked to make a pledge at the end of the session and these are followed up.
Example: CHSS stroke training

Current Care in Stroke is a course delivered in partnership between NHS Lothian, Chest Heart and Stroke Scotland (CHSS) and Vocal (voices of carers across Lothian). It is delivered to NHS and social care staff who work with people who have had a stroke and their carers. CHSS has been delivering training to NHS workers for over 10 years. Due to the impact stroke can have on the carers and families it was agreed to include it as a topic in Current Carer in Stroke part two. Vocal were involved in planning and delivering this aspect of the training. If they are available, a carer of someone who has had a stroke shares their caring experience as part of the training. Workers who have attended the training indicate in their evaluation that they have a better understanding of the needs of carers. They are often unaware that Vocal exists and have little knowledge of the services and support they provide before the training. “Good to know that support is available”

Example: Family support and young carers training

East Lothian Council funded a temporary development post within children’s services to deliver training to teaching staff, education welfare officers, voluntary sector staff and social workers. Gaps were identified in service provision including awareness of young carers. As part of the planning, research was conducted with young carers and their parents. There was also consultation with other partners, including the voluntary sector and social services. The aim of the training was to increase awareness of:

- factors contributing to the caring role that young carers have, such as disability, substance misuse, and mental health;
- the possible impact on children and young people who are young carers;
- to improve identification of support for young carers.

Training materials provide young carers’ views and experiences but they are not involved in the delivery of the session. At the end of the training, workers are asked – ‘what will you do differently in your role as a result of today?’

“I will try and factor into my thinking about particular young people, that they may be facing issues included in the definition of what a young carer is and bear this in mind when thinking about how to support the youngsters and their families”
One of the requirements of all social work programmes in Scotland is that they involved service users and carers. At the University of Dundee that duty is met through the activities of the CU group and its members. The group provides an opportunity for a user and carer prospective to be included in all aspects of how social work is taught at Dundee.

The group genuinely works in partnership with all of those involved in social work education. The group’s principles include no tokenism, each person has a voice, fair funding, plain English, bottom-up networking, see change from involvement, deciding on involvement, and diversity. All carers and users have experience of receiving social work services. The group influences and promotes best practice in social work education and informs the curriculum of social work programmes in the University.

The group has been instrumental in planning and delivering the Caring Experience module for the MSc in Social Work. This module involves students spending a minimum of 15 hours with carers and service users as they go about their everyday lives. Students gain valuable insight into the reality of the caring relationship. The carers and service users are also involved in the evaluation and assessment of the module.

You can view a video clip about the Caring Experience module on the EPiC portal.

"Taking part in the module allowed me to use theories and things that we’ve been learning in an academic sense and use them out in the real world." MSc student
Example: Developing carer awareness e-learning modules in partnership

VOCAL – Voices of Carers Across Lothian – was funded to provide the content for NHS Lothian’s e-learning for a carer awareness module. The NHS Lothian Carer Information Strategy stated the need for carer awareness training for workers. The content of the carer awareness modules were based on the strategy outcomes which had been informed by carer consultation.

VOCAL worked with NHS Lothian Learning and Training Development team to produce the training. At initial development meetings the content was discussed and the method of producing it. This was supported by NHS Lothian guidelines to writing module content. We used carers’ digital stories that had been made previously in partnership with NHS National Services to enable the carer’s voice to be heard.

This project was an example of partnership working between voluntary sector, public sector and private sector: VOCAL, NHS Lothian and LearnPro. NHS Lothian were able to provide the experience, Learnpro provided the platform and systems while VOCAL were able to provide content, the voice of unpaid carers and information about services which supported carers.

The modules have had wider benefits across NHS and beyond. Most boards in Scotland use LearnPro and we are able to share module scripts. The scripts can be edited by authors in other boards, and with the carer modules, they are encouraged to link with their local carer organisations.

Councils and other organisations that are signed up for learnPro authoring can also share the scripts, for example CHAS. Learnpro offer full training to those who want to adapt or develop modules and add their own branding.

Carers were consulted throughout the process – from the initial planning stages around the content through to user testing. Carers’ voices were also heard through the use of carer digital stories (4-8 minutes long). Focus groups of carers with differing caring roles such as parent carers and those working with carers who support people with an addiction were also consulted in the initial stages to ensure that the issues affecting these groups of carers was thoroughly researched and included. Carers reviewed and commented at draft stage. These comments were fed into the final materials. Carers then online tested the final product.

There are three modules which make up the Carers as Equal Partners e-learning programme:

- **Understanding and Supporting Carers** – this is mandatory for all frontline staff; new recruits complete it as part of their 12-week induction programme, existing staff complete it as part of their mandatory update (every 2 years)
- **Working in Partnership with Carers** – this is optional for clinical staff and is completed as part of their CPD
- **A Shift in Practice** – this is optional and was developed for those who could not attend face-to-face training sessions
In addition, Vocal offers face to face training for NHS Lothian nursing, medical and allied healthcare workers. The e-learning modules one and two are pre-requisite to the face to face training. An issue with any type of training and learning is that it relies on protected learning time, and that seems to be a real issue for workers. One of the benefits of e-learning from an organisational perspective is the ability to track how many have taken the module.

Each module has a clear aim and set of learning outcomes. These are particular to the level and purpose of the e-learning. These very much fit in with the aims of the NHS Lothian Carers Information Strategy, the outcomes from the Carers Strategy and the Equal Partners in Care core principles. The content of module 1 is currently being reviewed using the core principles. This will add to the process as workers can be confident that their learning is appropriate for their level of practice and responsibilities and fits into their professional learning frameworks.

You can view a video clip about developing the e-learning modules on the EPiC portal.

Example: A Day in the Life – The Ryan Harper Legacy

The project is a collaboration between PAMIS, a charity that supports people with complex needs and their family carers, and NHS Education for Scotland. They have developed a resource to support carers in their role as educators of the healthcare workforce. This will enable the workforce to develop person-centred skills, understand the context of life for the person they are providing services and their carers. It is aimed at pre-registration allied health professionals (AHPs) and trainee rehabilitation engineers (radiographers).

Initially a series of focus groups were run with service users and carers to identify what they felt the key learning and development needs of the AHP workforce were and whether there was interest in being involved in their education. The top priority identified was communication and attitudes. The PAMIS Grampian coordinator met with families to discuss the possibilities of a learning experience with them. These families were then core to the delivery of the training, attending the initial meetings and then having the students on placement with them. Key to this experience was the engagement with the family carers, ensuring that the learning and benefits were for all those engaged not just the learner.

The family carers and learners met prior to the experience in order to establish a relationship and to come together as ‘people’ rather than as health care professional visiting ‘patient’. They shared photographs and stories in order to develop a relationship that would support the inclusion of the learner in the life of the service user and their family.
Learning outcomes were identified by the learners and the educational institutions but also for those providing the experience. Pre-placement expectations were discussed and recorded and a post-experience evaluation was also carried out on both learner and the provider. The learners were able to gain an insight into the lives of people with complex health care needs. They also felt that their understanding of the challenges would change the way they would practice in the future. The family carers highlighted that they felt they were contributing to the development of better services as they were able to influence the education of the next generation of health care professionals. They also saw that the communication skills of those coming to the experience were enhanced and that the role they played as carers was appreciated.

HEI recognised the significant learning this experience provided and have embedded this approach in their curriculum for preregistration radiographers. The supervisor/manager within the service recognised the power of these placements and has also embedded this within the trainee engineer’s curriculum and there is interest in other parts of the service having similar experiences. Other HEIs have now approached the project to look for support in developing similar experiences for a range of the pre-registration AHPs. Currently the funding has come from NHS Education for Scotland. The next phase of this project is to provide a toolkit of “how to” run this type of learning. This will include costs and a sample contract for voluntary organisations to use with their learner partners.

Link to resource – Ryan Harper Legacy resource