The Ryan Harper Legacy

‘A day in the life of…’ experience influencing allied health professions future practice
“The painting on the front of this report is titled The Dove of Peace and Friendship – Painted by Craig Whinnett – with a helping hand from his friend Ryan Harper. Craig and Ryan had many friends during their lifetime, but when they were together there was a great sense of peacefulness.”

Jenny Whinnett, mother of Craig
The Ryan Harper Legacy

‘A day in the life of…’ experience influencing allied health professions future practice

“It was during the last few months of his life that Ryan participated in the ‘a day in the life of…’ Pilot Project to support the training of radiography students. We recognise that even though he was unwell while taking part, his inclusion had benefits to the student who participated with him, and we hope that this Pilot Project will go on to inspire other professions to use this type of training.

Ryan’s family are proud to have taken part in the Pilot and that Ryan’s memory has been honoured in this way.”

Elizabeth Harper, mother of Ryan Harper

Acknowledgements

The Pilot Project teams from PAMIS, Robert Gordon University, School of Health Sciences and NHS Education for Scotland AHP PEF Programme would like to thank the families and students who participated in the project for their enthusiasm and commitment.

In memory of Ryan, the young man who actively contributed to this Pilot, this type of practice based learning will be known as The Ryan Harper Legacy – a day in the life of experience.
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1.0 Foreword

It is with great pleasure that I present this report on behalf of a partnership of people who have worked with NHS Education for Scotland Allied Health Professions (AHP) Practice Education Facilitation (PEF) Programme to develop learning opportunities that can influence the future practice of AHPs.

The AHP PEF Programme has from the onset sought out opportunities to engage with service users and carers as partners in education. This project, described within this report, was born from an initial consultation with service users and carers in East Renfrewshire (NES 2007), which highlighted key areas for pre and post registration education in relation to:

- AHP communication skills
- AHP attitudinal skills
- Education and learning issues
- Service users and carers experience with students

We therefore sought to develop practice based education experiences that optimised opportunities to address these issues and commissioned this work. PAMIS, a voluntary organisation who support people with complex needs and their carers, and Robert Gordon University (RGU) radiography preregistration programme were commissioned to develop ‘a day in the life of…’ experience that has had an impact on both the students and the delivery of preregistration radiography in RGU.

Will it change future practice?

This depends on all of us reading and then reflecting on what we are told in this report – encouraging and supporting these students to live their expectations in their next placements and finally as practitioners in the services they enter. It also depends on what we as educators, managers, practitioners, learners and service developers choose to do with this transferable project.
Ryan Harper and his family gave willingly their time and support to offer an insight into their lives as did five other families. Ryan died shortly after the project finished but his mother remained involved in the evaluation and writing of the report. She has generously agreed that this report and practice placement opportunity will be his legacy. The Ryan Harper Legacy will provide a structure for practice placement opportunities for all learners. Mrs Harper asks that:

“this Pilot Project will go on to inspire other professions to use this type of training”

I am delighted that RGU preregistration radiography department have embedded the Ryan Harper experience within their core curriculum. NHS Education for Scotland are continuing work with PAMIS and other carer and service user organisations so that the Ryan Harper experience is available for other learners and programmes.

What will you do?

Jenny Miller, AHP Programme Lead for Practice Education, NHS Education for Scotland
2.0 Context

Complaints about communication, staff attitude and dignity are still the top causes of complaint to the Scottish Public Services Ombudsman (SPSO) (SPSO, 2010). The Cochrane Collaboration intervention review by Lewin et al (2001) suggest that the issues with communication in health care may be due to the practitioners neglecting the skills of person centred care, in favour of concentration on disease and it’s management.

Delivering person centred healthcare is a priority for the NHS (Scottish Government (SG) 2010) (figure 1) but how will this be realised and how can health practitioners be prepared to meet this expectation? These were questions that supported the development of a project to prepare radiographers for the workplace. The project recognised the need for radiography students to engage with those who use their services in order to developing an understanding of their priorities and specific needs, a person centred approach (SGHD 2010).

“Mutually beneficial partnerships between patients, their families and those delivering healthcare services, which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making.”

(The Healthcare Quality Strategy for NHSScotland, SG 2010)

Figure 1 – Quality Ambition – Person Centred Care

The development of health care curriculum to support this agenda where service users and carers are actively involved in all aspects of education (Skills for Health 2008) has expanded over the past decade, but with limited evidence that service user involvement leads to changes in behaviour in practice or to the service user health care outcomes (Morgan and Jones 2009). However, there is conclusive evidence that the teaching of communication and person centred skills is more effective when using experiential and practice based methods (Aspergren 1999, Berkhof et al 2011). Furthermore, Repper and Breeze (2007) highlight that if education and training is to support the development of services that reflect the priorities of those that use and need them, then it requires to be developed in partnership, bringing together service users and service providers. This approach is already embraced within the curriculum for social work education (DoH 2002) and the Ryan Harper Legacy has used a model developed within social work practice placements.
The Ryan Harper legacy builds on work that had been undertaken by NHS Education for Scotland (2008) that sought the opinions of service users and carers in East Renfrewshire as to the educational needs of Allied Health Professions. The top priorities were:

- AHP communication skills
- AHP attitudinal skills
- Education and learning issues
- Service users and carers experience with students

The top two of these mirrored the core complaints against the NHS (SPSO, 2008, 2010).

In 2009, NHS Education for Scotland commissioned RGU preregistration radiography programme, and PAMIS to develop ‘a day in the life of...’ experience. This experience has become known as the Ryan Harper Legacy, in memory of one of the participants who enabled students to have an insight into ‘a day in his life’.
3.0 Background

The Pilot Project – PAMIS/Robert Gordon University Partnership

In 2006, at an NHS Education for Scotland practice education event, in one of the NHS Scottish health boards a parent of a young man with profound and multiple learning/intellectual disabilities (PMILD) told her story to a group of AHPs. One particularly poignant aspect was her visit to the radiography department where her experience had been stressful. She related the hours of care activities she required to carry out for her son before she was able to leave for the hospital. An appointment at 09.00am meant she had risen to get her son ready at 05.30am. A 30-minute drive to the hospital had taken an extra 20 minutes at that time of the day. There were access to disabled parking issues that meant she was parked a considerable distance from the hospital. When she finally arrived five minutes late for the appointment her reception was very frosty and she explained to the audience how that had made her feel. She suggested that if the radiographers had been given an insight into the tasks and time spent in order to arrive at the appointment, then they may have been more sympathetic to her position. The audience were silent; the impact of this honest, clear, gently critical story had made an impact.

NHS Education for Scotland commissioned a voluntary sector organisation PAMIS (Promoting A More Inclusive Scotland – in partnership with people with profound learning disabilities and their carers) and the preregistration Diagnostic Radiography course at Robert Gordon University (RGU) to work in partnership to develop ‘a day in the life of...’ experience for six undergraduate Diagnostic Radiography students.

The aim of the Pilot Project was:

To explore the impact on student development, including their attitude, communication and person centred skills, by spending dedicated time with service users and their carers.
4.0 Selecting the participants

4.1 Participating Families

Through their work within Grampian PAMIS were actively involved with a number of families with sons or daughters with PMLD. The Co-ordinator met with a number of these to explain the purpose of the project and following further discussion with the university tutors recruited seven families to participate. These families covered a spectrum of the family such as a father as the main carer, a family that had a number of generations sharing the home and several of the families where the parent had teaching skills. The mix also covered families caring for children with PMLD and a family caring for a young adult with PMLD.

All the families gave written agreement (appendix 1) to the students spending time in the family home, and in participating in the evaluation following the visits.

4.2 Participating Students

Seven stage two students from the BSc (Hons) Diagnostic Radiography course were selected from seventeen applicants to participate in the project.

Selection was undertaken by the course management team based on previous academic and clinical performance and on the individual student’s rationale for participating.

All participating students gave their written agreement to fulfil the required time commitment of the project and to contribute to post project evaluation. They also agreed to the placement agreement requirements (appendix 2) and this was signed by both the student and PAMIS.

5.0 Governance

Prior to commencing student and family visits a quality governance framework was established to ensure the safety of both the families and the students.

Robert Gordon University extended professional indemnity insurance to all students while working within the families homes and whilst visiting school, colleges and places of work.

The student was required to comply with the Health Professions Council (HPC), Guides on Conduct and Ethics for Students (HPC 2009). All students were student members of the Society and College of Radiographers and were bound by their requirements for confidentiality and Codes of Professional Conduct and Ethics (Society of Radiographers (SoR) 2008).
Through the use of a Lone Working Policy each student was required to take all reasonable and practicable actions to ensure their own health, safety and welfare and those of the child, family and carers.

6.0 Preparation

6.1 Participating Families

To prepare the families the PAMIS Co-ordinator made two home visits to each of the families participating to discuss in detail the plan for the Pilot, and what would be involved during the student’s visit to the home. The PAMIS Co-ordinator also discussed with the families their hopes and wishes for the outcome of the Pilot and its implications for the student’s future practice.

The participating families then had the opportunity to meet up together with the PAMIS Co-ordinator to discuss the issues of safety, insurance and what was to be expected from both families and students during the visits (appendix 3). During this meeting the families were also given information about the training of the participating students and they were reassured regarding disclosure checks. The families also had the opportunity to discuss together the possible benefits of the experience for both the students and themselves and families.

6.2 Participating Students

Each student had a minimum of two years undergraduate clinical experience and had completed first aid, CPR (cardiopulmonary resuscitation), infection control, moving & handling training and received instruction on appropriate data protection and confidentiality of service user information. In addition all students had successfully completed heath screening and enhanced disclosure criminal records checks.

Prior to meeting families the student cohort met with the PAMIS Co-ordinator to discuss the project. This aspect of preparation was considered essential in order to give the students a realistic understanding of the degree of disability of the participating children and young people, their care needs and the challenges facing the families and their carers.

Students were encouraged to identify their own learning needs and action plan accordingly and were supplied with extensive information on PAMIS and the people with whom they worked.
6.3 Initial Meeting of Families and Students

A key feature of preparation was an initial meeting of parents and students prior to visits in the families’ homes. This initial meeting gave families and students an opportunity to introduce themselves but also importantly to identify any preparation and support needs that may be required to make the experience successful for both parties.

The meeting was held at the university over a lunch time. This gave the family carers the sense of the importance of the Pilot, and their credibility as skilled co-trainers for this experience. Travel expenses and carer expenses were available for all the families.

The family carers and students had been invited to bring information and photos of their families to this meeting, so that important information could be shared and barriers reduced. This was important to ensure that the students felt comfortable when introduced to the son or daughter of the family carer within the home, as this was vital to the success of the Pilot. It also recognised the importance of ‘story telling’ as a media to explore personal identity and values (Denning 2001). Given the short period of time that was available for the students and the families to develop a relationship this sharing of ‘stories’ was invaluable and supported the success of the project. This meeting and sharing was well received, with family carers and students sitting comfortably over lunch, sharing family information.

Due to illness and fragility of one family member with PMLD, the meeting with the student had to be held at a later date at the PAMIS office, but this meeting was also very relaxed and informative for the family carer and the student involved.

7.0 The Experience – The visits to families

Each student visited with their partner families on at least three occasions totalling a minimum of twelve hours. The timeframe, duration and location of each visit was planned to give the student the fullest opportunity to experience a typical day in the life of the family and their carers.

The order of visits were determined by the family but in all instances commenced with a late afternoon visit to the child or young adult’s home. This choice was made by all families who considered it to be a less sensitive time of the day and allowed the student to be introduced to the young person and their surrounding in a more relaxed environment. The afternoon visit enabled the student to be involved with the child’s or young adult’s leisure activities, mealtimes and preparation for bedtime. These visits also gave the student an opportunity to interact with other members of the family including parents, siblings and extended family members.
An early morning visit to the child or young adult’s home permitted the student to be involved in the personal care of the young person including bathing, clothing and preparation for daily activities. This visit in particular enabled the students to gain first hand experience around the challenges of caring for a young person with profound and multiple learning disabilities and very complex health needs in an environment which is not specifically designed nor equipped for the purpose. It also provided the students insight into the demands placed upon the child’s carers and the degree of complex technical care that must be provided by the families.

The third visit was scheduled to coincide with the young person’s daily activities including school (appendix 4 and 5), vocational employment and where possible healthcare appointments. This day time visit afforded the student group a diverse range of experiences but collectively demonstrated to them the immense challenges of daily life for the young person and their carers but also the normal happy environment that all involved worked hard to ensure.

8.0 The Outcomes – Parents and Families

Parent experiences with the students were evaluated using a questionnaire (appendix 6) that enabled reflective outcomes, coupled with discussions with the PAMIS Co-ordinator.

8.1 How well did the students explain the purpose of the Pilot?

The parents felt the ability of the students to discuss this was dependant on how confident they were. Some could express what they perceived to be the purpose of the Pilot both to the families, and other supports to the families, while others felt that this had been covered at the joint meeting at the University.

8.2 How well did the students communicate what support they could give, and how easy were they to talk to?

All the families were delighted with the interest and motivation of the students to learn about their family members. Some of the students were more confident than others to give family carers information on what support they could offer, but all willingly gave practical support during the visits. All families were impressed with the student’s warmth, genuine interest in their family and ability to talk with themselves and their family member with PMLD without showing any awkwardness. All the parents believed that with progression through the course and with increased confidence the students would make confident, communicative professional radiographers.
8.3 How well did the students listen to the family?
All the families agreed on one important aspect of this area of the Pilot. They are so used to having to impart information about their family member to a multitude of professionals, that they were too ready to feed information to the students, instead of enabling them to ask appropriate questions. They all said that if they participate again, they would remedy this, and encourage the student to ask what they needed to learn. However, all the information given to the students did appear to inspire them to ask many relevant questions to build on what had been shared with them, and some relayed very quickly how the information would impact on their future practice.

8.4 How appropriately did the students involve themselves with the son/daughter with PMLD and did they behave professionally?
All the parents recognised that the students had never had direct contact with young people with PMLD, yet they all stated that the students talked with their sons/daughters and ‘not over them’ as parents experience on a regular basis from professionals. The students all gained confidence during the visits and actively participated in play and hands-on support to the carers. All the students highlighted that they had gained a real insight into how demanding physically and mentally it was for family carers to manage on a daily basis with the personal and emotional care of all members of the family. The parents all highlighted that although the students were so young in years, all had displayed an enormous amount of maturity, especially as a number of the young people with PMLD had been suffering serious health problems at the time.

8.5 How did the students believe this experience would impact on their future practice?
Some of the students needed to be prompted to think about this, but all of them stated that the experience had made a huge difference in their perception of disability, and the needs of people in clinical settings. Some had indicated the need to take a hard look at how clinics are managed and how the machinery is set up for individuals with profound disabilities and unusual body shape, such as making the individuals more comfortable, and protecting their body shape.

Some students also emphasised the importance of recognising that the ‘parent knows their son/daughter best’. Some students highlighted the need for flexibility within clinics for times and length of appointments and thinking about the effect of noise on individuals with PMLD. They also recognised the importance of having the support of someone who understands the individual’s communication, although some students did emphasise this did not negate their feeling of responsibility in ensuring they got it right.
8.6 How has this experience been helpful to the family?
All the family carers believed this to be a very valuable experience to have participated in. They believe that this experience of family carers as co-trainers should be rolled out to all health science students, and especially student doctors.

The families anticipate that the experience will have an impact on the students maintaining best practice in their own future career, but also influencing better practice in other peers and colleagues through disseminating their experiences.

All the families stated that they would wish to participate in the experience again, but all stated that they would improve their teaching technique, and enable the student’s to have the confidence to ask more questions.

8.7 Examples of some of the student’s experiences
• Bathing and dressing
• Home visit of the hairdresser
• Pushing a heavy wheelchair up and down kerbs
• Changing a button gastrostomy/care of stoma site
• Information on feeding pumps and equipment
• Information on medication protocols
• Moving and handling in the home and different equipment being used
• Splinting
• Attending fracture clinic
• Attending neurology clinic
• Young adult being very unwell
• Access issues e.g.
  • Transport issues
  • Parking
  • Lack of changing facilities
  • Broken disabled lifts

“I enjoyed the opportunity of being a part of the radiographers training with the hope that it will have an influence on their future practice”

“I would like this to be the start of an ongoing project across all medical disciplines”

Families involved in the Ryan Harper Legacy Pilot Project for radiography
9.0 The Outcomes – the students

Student experiences were evaluated using personal reflection outcomes and student consensus group discussion.

9.1 Is this type of experience valuable to students?

Students considered that there was real value in this experience as it gave them insight into the daily lives and challenges faced by their patients, families and carers. It also allowed the students to see that despite their unique set of challenges these were families wanting to lead ‘normal’ lives.

None of the students had previous experience of working with young people with complex and profound disabilities and their families either socially or professionally. As a consequence all students agreed that a significant gap in their knowledge and understanding had been filled and this would have a profound effect on their future clinical and professional practice.

9.2 What have you learnt from the experience?

This experience has given the students an opportunity to see the impact that disability had on the young people and their families.

Students felt the experience had enhanced their empathy and sensitivity towards their patients/service users and would undoubtedly increase their appreciation of the daily challenges faced by people from all backgrounds.

Students found that the home visits taught them important approaches to caring for young people with a disability such as individualising care to meet the persons’ individual needs and the focus on quality of life. It also gave them significantly greater insight into the need for this individualised approach and that protocolised care may not be effective in every situation.

Importantly for the diagnostic radiography student who rarely spends lengthy time periods with a patient/service user, this opportunity allowed the student to build a more substantial relationship, building rapport, warmth and friendship. As a consequence development of more effective communication skills was a positive outcome of the experience.

“A significant gap in my knowledge and understanding has been filled”

“Gave me a real insight into the daily lives and challenges faced by the person and their families”

Student Radiographers on the Ryan Harper Legacy Pilot Project
From a learning perspective the opportunity to follow a day in the life of the young person and their individual care needs gave students depth to their understanding. They had an opportunity to question their own knowledge base, challenge their own understanding. Rather than a classroom based exercise, students were interested, inspired and motivated to investigate further and many students undertook significant personal study to become more familiar with the young person’s disability, their medical care and psychological support.

9.3 How will it change the care you give your patients?
Students reported that they felt that in order to manage patients/service users care successfully, they as radiographers needed to understand and appreciate the influence of social, psychological, and environmental factors on the persons everyday lives. Students felt that their whole approach to person centeredness would change as a consequence of this experience. There was a common recognition that in future students would give greater attention to preparation for the investigations of the people they were imaging both in terms of physical preparation for the investigation but also in terms of preparing for the individual ‘person’.

Students also felt that the experience would change their personal attitudes towards responsibility for their patients/service users. Getting to know the individual brought with it a sense of responsibility and conscientiousness, their expectations of the quality of care for these young people has increased and they now want positive outcomes for the young people and their families.

9.4 How has the experience affected you?
On a personal basis all students agreed that the project had had a far greater impact than they might have initially anticipated. Some students became very involved with the family and developed a personal and emotional attachment to the young people.

Greater understanding of the challenges faced by these families also led to frustration in some students to the perceived inadequacies of care and support provided by NHS and social services.
9.5 Key Messages from Student Evaluations
The two key messages from student evaluation were:
1. Patients/service users are individuals and need individual care.
2. Sound professional practice is important but empathy and sensitivity are also essential for person centred care.

10.0 Further Developments
10.1 PAMIS
All the families taking part have indicated that they wish to continue to participate in this experience.

Although successful this Pilot has highlighted the need for a more in-depth preparatory programme that would support the families’ roles as educators. PAMIS has experience of training family carers as trainers and will take this forward in the next phase of this project.

PAMIS wishes to continue to work in partnership with NHS Education for Scotland and RGU to build on the ‘a day in the life of...’ experience for Health Care students, and to support the dissemination of this experience to all students in the cohort who did not actually have the opportunity to participate directly with a family. It was recognised that the participating students and families had been carefully selected, but this now needs to be examined, as all students will need to be able to work effectively with all patients/service users who come into the clinic.

PAMIS is also very keen to be involved in following this cohort of students through their continuing training to see how this experience continues to influence their practice. Developing a longitudinal study to follow them once they start on their career may assist in seeing the influence of this experience on their professional colleagues and into their clinical practice.

10.2 RGU Radiography Course Team Recommendations
The following recommendations were made to the Course Management Team Review in October 2010 for ongoing development of this project:
1. The participating students will be invited to comment on how this experience influences future clinical places over the next two years of their undergraduate programme.
2. The project team recognise that the participating students were carefully selected for this project but a similarly successful outcome for students and families could not be assured with a wider student cohort. However the value of the experience for the development of patient centred skills and attitudes is equally recognised. The recommendation to the course team was to build home visits with service users into a substantive feature of the undergraduate programme. Therefore a programme of liaison with a range of community and carer groups will be undertaken to facilitate visits during 2nd and 3rd year matching participating volunteers to individual students.

3. Effective communication has been identified by the families as an essential skill in the participating students and the course team will be encouraged to extend the existing patient volunteer scheme to include clinical communication scenarios.

4. Effective preparation and support of both the families and the students was identified by PAMIS and School of Health Sciences staff as a key requirement for success in the project. However, it was recognised by this Pilot Project that a more comprehensive preparation programme was ideally required. Further developments from this project must therefore include a preparatory programme, which supports students to develop the skills necessary to build effective but professional working relationships with patients/service users, families and carers.

10.3 NES AHP PEF Programme Recommendations

1. The learning from this Pilot will be disseminated widely and built upon within the AHP PEF Programme.

2. The AHP PEF Programme will support RGU and PAMIS to further develop the induction resources and to explore other practice educational opportunities that enhance the person centred and communication skills of the AHP workforce.

3. A further Pilot will be undertaken exploring the benefits of the Ryan Harper Legacy for other parts of the AHP workforce. During 2011/12 staff within a wheelchair service will have the opportunity to undertake day in the life experiences. This enhances the NES educational resources developed for wheelchair and seating services and provides a further opportunity to evaluate this type of workbased learning.

4. The AHP PEF Programme will enable other service user and carer groups to access resources to support further Ryan Harper Legacy experiences.

5. The AHP PEF Programme will further explore opportunities to learn with and from service users and carers.
Conclusions and next steps
This small scale project has had big scale impact on all those involved. The commitment of the families and young people with PMLD has made a significant impact on the undergraduate curriculum for diagnostic radiographers at Robert Gordon University.

The recommendations presented to the Course Management Review were accepted and further developments are progressing to support all preregistration radiographers at RGU to undertake experiences that enable them to develop person centred skills that can be taken with them into the clinical setting.

PAMIS and RGU are developing the preparatory sessions for both students and families enhancing the opportunities within this style of placement.

This experience does come at a cost both in personal time from those providing the day in the life experience and those supporting the learners. The costs associated with supporting this need to be embraced if this project is to be further developed.

This experience has far wider implications and NHS Education for Scotland commissioned a scoping exercise to identify further organisations that can support this educational opportunity for a wider range of the AHP workforce. A programme of work with another third sector organisation, Capability Scotland, is also underway and a component of this will support the rolling out of the Ryan Harper Legacy to the wider workforce.

The involvement of service users and carers in the education of the health and social care workforce has an ethical and statutory mandate (SG 2010, Skills for health 2008), the partnership approach adopted within the Ryan Harper Legacy should be considered as a model for future health and social care educational developments.
References


Morgan A, and Jones D, 2009, Perceptions of service user and carer involvement in health care education and impact on students’ knowledge and practice: A literature review. Medical Teacher. Vol 31, pp. 82-95

‘A day in the life of...’ experience influencing allied health professions future practice


Appendices

Appendix 1  Letter to families and attached permission slips
Appendix 2  Practice Learning Agreement
Appendix 3  ‘A day in the life of…’ Pilot Project
Appendix 4  Letter to a school
Appendix 5  Evaluation form
Appendix 6  Family Carers Evaluation
Appendix 1

Dear

Link meetings for families participating in ‘a day in the life of…’

I have now worked on the plans for this exciting Pilot that your family wish to participate in. I sincerely hope that you and your family will enjoy the experience, knowing that you will have a real impact on the students participating with you in this experience.

Lesley Forsyth, the tutor in Radiography from Robert Gordon University, working with me on the Pilot has stated that she has 6 very keen students to link up with the families. She also stated that nearly 20 students came forward to volunteer for the family experience. I think it is very positive to know the amount of interest in learning directly from you and your family, and the recognition of the skills you have to support these students.

I wish to invite you to a Link Meeting on 20 April, 11am at Robert Gordon University, Garthdee Road, Aberdeen, where you will be given important information about the Pilot, and you will have the opportunity to meet Lesley Forsyth and the student who will be linked to your family. Please bring information about your family and if possible photographs of your son/daughter. I do hope that you will try to attend this important meeting. If you require care for your son/daughter, we will fund the cost of your short break provider. If it is impossible to attend, I will make a home visit as soon as possible to update you on the important information.

I also attach permission slips for participating in this project and for using images or recordings for our reports etc.

I look forward to seeing you and sharing more information on this exciting Pilot.

Yours sincerely

Jenny Whinnett
PAMIS Grampian Co-ordinator
Appendix 1 attachments

PAMIS, NHS Education for Scotland and Robert Gordon University have requested your support in a Pilot Project, ‘a day in the life of...’.

We would like to ask for your permission to allow PAMIS to use images including stills photographs and film footage of you in:

1. Our printed publications such as reports and magazines.
3. Our digital resources such as videos, CD-ROMs, DVDs and presentations.
4. Other online channels used by PAMIS or its partner organisations.

PAMIS will not pass on the images or recordings to be used by any other organisation (apart from our partner organisations) except to illustrate features promoting the work of PAMIS or partner agencies.

If you agree to allow us to use the images, please complete the details below.

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If you have any questions, please contact Jenny Whinnett Tel: 01224 784456
Appendix 1 attachments

PAMIS, NHS Education for Scotland and Robert Gordon University have requested your support in a Pilot Project, ‘a day in the life of…’

Following the information we have provided you and as a result of the interest you have shown in participating in this project we are asking that you now confirm your willingness to participate in the learning experience, the subsequent evaluation and agree to the experience and your evaluations being used as the basis of a report.

If you agree please complete the details below.

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If you have any questions, please contact Jenny Whinnett Tel: 01224 784456
### Appendix 2

**PAMIS/NHS Education for Scotland/Robert Gordon University Pilot Project**

‘a day in the life of…’

#### Practice Learning Agreement

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<tbody>
<tr>
<td>Name of the family carer:</td>
<td></td>
</tr>
<tr>
<td>Name of Practice Supervisor:</td>
<td>Jenny Whinnett</td>
</tr>
<tr>
<td>Practice Learning Agency:</td>
<td><strong>PAMIS</strong></td>
</tr>
</tbody>
</table>
| Address: | Unit 5 Badentoy Business Centre  
| | Badentoy Crescent  
| | Portlethen  
| | AB12 4YD |
| Telephone No: | 01224 784456 |
| Dates and Duration of Practice Learning Opportunity: |  |
| Morning Visit: |  |
| Daytime Visit: |  |
| Afternoon/Evening Visit: |  |
| Any other visit: |  |
| Agency Description: | **PAMIS** is a voluntary organisation and a registered charity |
PAMIS has a commitment to ensure that:

- People with profound and multiple learning disabilities are valued both as individuals and in the contribution they make to the community
- They should receive all the support needed to realise their full potential
- Their right to a full life shaped by personal choice, abilities and needs underlies all provision and policy affecting their lives
- The knowledge and experience of family carers is recognised, and that their views are fully taken into account in service development

To achieve this PAMIS offers families:

- Practical help, advice, training and information
- Individual support, and contact with other families
- Assistance with achieving better access to community resources, whether mainstream or specialist
- The opportunity to influence policy and services significantly, both at local and national levels

PAMIS is a member of the Scottish Consortium for Learning Disability.

**Practical arrangements:**

- **Title student will use**
The student will be known as a student radiographer for the Pilot.

- **Hours of work**
Pilot will take place over three days.
  - Morning shift from time of waking until leaving for school/day service
  - Shift during day at school/day service, or accompanying family to appointment with son/daughter
  - Evening shift following return home from school/day service until settled in bed (up to eight hours)

- **Legislative framework**
We work within the bounds of relevant legislation, in particular the Data Protection acts and the Access to Personal Files Act 1987.
• Security
  • Information about those we work with is kept in locked cabinets. Electronic data is password protected
  • All students involved in this Pilot Project will have undergone Enhanced Disclosure

• Confidentiality

PAMIS recognises that the people we work with have a right to privacy regarding information about their lives and wishes to be recognised as a trustworthy organisation.

Information about families (or others) may be discussed with other staff members, but only on a ‘need to know’ basis and in the interests of family concerned. Information of any sort about families cannot be disclosed outwith PAMIS without clear permission of those concerned.

• Suspicion of exploitation or abuse

PAMIS works with vulnerable people. There may be occasions when staff has good reason to suspect exploitation or abuse of people with learning disabilities (or others). Where staff suspects exploitation or abuse they should inform their tutor or PAMIS co-Co-ordinator immediately. The Co-ordinator may take further advice from within PAMIS, but in cases where individuals may come to significant harm; a decision on action will be made on the same working day.

Where criminal acts are suspected, the police will be informed. Where there is a social work involvement the care manager will be contacted, or in the absence of a carer manager the local area office will be informed.

In relation to ensuring PAMIS policy on confidentiality is adhered to while the student is in place with the family the PAMIS Co-ordinator will ensure families are contacted and asked permission to share information before access to family information will be available to the student. Once permission is given information can be used in evaluations and reports.

• Student’s learning plan: Work allocated to the student will be appropriate and will allow the student to meet their learning needs as outlined in 2nd Year BSc Hons. Diagnostic Radiography course.
• **Learning needs of the student**
  - Introduction to PAMIS and its values
  - Personal experiences with Allied Health Professions (AHPs)
  - The many different AHPs that may be involved in the life of someone with PMLD
  - Positive and negative experiences with AHPs
  - Joint working approaches/shared skills – shared knowledge
  - Parents, carers, service users as co-trainers.

• **Learning opportunities available to meet the student’s needs and allow them to evidence progress in relation to the 2nd year BSc Hons. Diagnostic Radiography Course.**

Opportunity to meet family carers caring for people with profound and multiple learning disabilities, and who are using the PAMIS Family Support Service. The student will have the opportunity to gain experience of direct work with individuals and family carers as well as develop an understanding of the constraints and challenges of their family lives. The student will have a real opportunity to see the young person with profound and multiple learning disabilities as a valuable individual who communicates by alternative methods. The opportunity will be given to gain an understanding around the role of the Welfare Guardian, the Adults with Incapacity Scotland (2000) Act and other relevant legislation.

**Expectations of student**

To experience a day in the life of a family caring for a son/daughter with profound and multiple learning disabilities.

The student is expected to:

• work alongside the family carer in supporting their son/daughter within the family home
• establish and maintain trust and confidence of service users and family carers
• respect the rights of service users while ensuring their safety and the safety of others
• participate alongside school/day centre staff with the son/daughter
• attend any appointments with the family carer for their son/daughter during the period of the Pilot
• prepare for feedback, draw on Reflective Diary entries as a base for discussion of their learning and provide evaluation and feedback for PAMIS and RGU
• take responsibility for own learning and reflect upon and evaluate own performance through the use of a reflective diary
• ensure that their car is adequately insured if they use it for the Pilot
• agree to inform the tutor if experiencing any difficulties with aspects of the work
• agree to respect confidentiality of the family
• agree to commit to the time requirements and visits

**Expectations of PAMIS Co-ordinator**

• To provide the student with an appropriate induction to PAMIS
• To allocate student an appropriate family carer placement that will enable them to meet learning outcomes
• To help the student integrate knowledge and practice
• To help the student develop anti discriminatory and oppressive practice
• To help the student begin to understand working in partnership with family carers and their sons/daughters
• To meet with the tutor and student as required
• To provide the student with verbal feedback on their progress at the end of the Pilot
• To facilitate the gathering of feedback from the linked family carer
• To provide a Feedback Report on the student at the end of the Pilot that the student has had the opportunity to read and comment on before submission

**Evaluation of student’s work**

Information will be gathered through, feedback from family carers, reflective diary and evaluation interview.

**Procedures for dealing with concerns about student progress**

If there is cause for concern regarding the student the tutor and PAMIS Co-ordinator will be informed, and will reserve the right to withdraw the student from the visit.

**Procedures for dealing with general concerns/disagreements/complaints**

The student and PAMIS Co-ordinator will initially attempt to resolve any difficulties between themselves. If unsuccessful, the tutor or PAMIS Director may be approached.

If there are any queries or uncertainties about any aspects of the ‘a day in the life of…’ Pilot Project, PAMIS Co-ordinator or student should contact the student’s tutor for clarification.

<table>
<thead>
<tr>
<th>Signed</th>
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<tbody>
<tr>
<td><strong>PAMIS Co-ordinator</strong></td>
<td><strong>Student</strong></td>
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<tr>
<td>Date</td>
<td>Date</td>
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Appendix 3

Robert Gordon University/PAMIS/NHS Education for Scotland
BSc (Hons) Diagnostic Radiography
‘A day in the life of…’ Pilot Project

<table>
<thead>
<tr>
<th>Date/Week</th>
<th>Activity</th>
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<tbody>
<tr>
<td>Monday 12 April 11am – 1pm</td>
<td>Student Briefing</td>
</tr>
<tr>
<td>Tuesday 20 April 11am – 1pm</td>
<td>Students/Families Introductions</td>
</tr>
<tr>
<td>22 – 23 April</td>
<td>Student visits to families – by arrangement between student and families</td>
</tr>
<tr>
<td>Week commencing 26 April (not Monday 26 April)</td>
<td>Student visits to families – by arrangement between student and families</td>
</tr>
<tr>
<td>Week commencing 3 May April (not Thursday 6 May)</td>
<td>Student visits to families – by arrangement between student and families</td>
</tr>
<tr>
<td>Week commencing 10 May (not Friday 14 May)</td>
<td>Student visits to families – by arrangement between student and families</td>
</tr>
<tr>
<td>Week commencing 17 May</td>
<td>Assessment prep for module HS2034</td>
</tr>
<tr>
<td>Friday 21 May</td>
<td>Assessment for module HS2034</td>
</tr>
<tr>
<td>Monday 24 May</td>
<td>PAMIS Feedback to Students and Student RGU Evaluation Interviews</td>
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</table>

Student visits to families
Session one: Approximately 7am to 8.30am in family home
Session two: Approximately 10am to 2.00pm at child’s school
Session three: Approximately 3pm to 9.00pm in family home
Appendix 4

Letter to a school

Dear

*PAMIS, NHS Education for Scotland, Robert Gordon University Pilot Project ‘a day in the life of…’*

I am contacting you to request your support to the above project through two families who have agreed to participate in this exciting work with student radiographers. Mr A daughter B, and Mrs C daughter D, both attend *School*, and will be supporting the students to have an experience of what it is like for families to care for someone with profound and multiple learning disabilities.

The students will be spending time with the family in the morning to see the early routine, and also from the time the young person goes home from school until bedtime. The student may also attend any appointments the young person has during this experience.

We would also appreciate the opportunity for the student to spend time at the school with the young person to see a little of their school experience.

I will inform the students involved with B and D to contact you to arrange their visits, so that you can organise them so as not to be too intrusive. The students have all gone through Enhanced Disclosures, and Moving & Handling training.

I enclose the timetable as given by Lesley Forsyth, the tutor involved with the Pilot Project, to give you an idea of when the students may be wishing to attend the school.

I thank you in advance, hoping that you will be able to support this exciting new Pilot, with the future belief this experience will have a very positive influence on the students future practice and understanding of the constraints on families caring for young people with profound and multiple learning disabilities.

Please contact me if you would like any further information on the Pilot or have any other queries.

Yours sincerely

Jenny Whinnett *PAMIS* Grampian Co-ordinator
## Appendix 5

NHS Education for Scotland, Robert Gordon University, *PAMIS* Pilot  
School/day service Evaluation form  

‘A day in the life of…’ supporting the education of 1st Year Radiography students.

<table>
<thead>
<tr>
<th>Name of student:</th>
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<thead>
<tr>
<th>Family linked with:</th>
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<table>
<thead>
<tr>
<th>Date of visit:</th>
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<table>
<thead>
<tr>
<th>School/day service visited:</th>
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<table>
<thead>
<tr>
<th>1. Did the student arrive on time?</th>
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<tr>
<th>2. Did the student participate within the class/day centre?</th>
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<table>
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<tr>
<th>3. Which member of staff was the student linked to?</th>
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<tr>
<th>4. Did the student ask any appropriate questions about the daily life within the school/day service of the person with PMLD they had been linked to with the Pilot?</th>
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<tr>
<th>5. How did the student interact with individuals within the class/day centre?</th>
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<tr>
<th>6. Have you any further comments you would like to make that would support the student’s experience?</th>
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</table>
Appendix 6

NHS Education for Scotland/Robert Gordon University/PAMIS Pilot Project
‘a day in the life of…’

Family Carers Evaluation

Guidance Note
This evaluation will be used in addition to the student’s evaluation and the feedback from the Course Tutor/Link Supervisor, to assess the student’s progress and understanding.

Use the document as you see fit, e.g. fill in the answers to each area suggested below, or write your evaluation comment at the end of the document.

The questions provided may help students to think of the areas they wish to ask the family carer about. This in turn should open up dialogue between the family and the student. However, the questions and methods of feedback should be adapted to take into account the context of the situation. In relation to children this should take into account the age and stage of development. Language in all situations should be jargon free and easily understood.

We suggest that the family carer completes the evaluation form over the course of the student’s placement, or at the end, whichever is most suitable to the carer. Write or type the responses in the boxes – these extend as necessary.
Areas to consider

1. How well did the student explain the purpose of the experience with the family?

2. Was the student able to give the family enough information on the support he/she would provide? What further information would have helped?

3. Did the family carer find the student easy to talk to? What made it easy?
4. Did the student listen well to the family?
   How did the family judge this?

5. Did the student involve themselves with the family and their son/daughter’s
care appropriately, i.e. communicate with son/daughter and listen to family
carer views?
   Can family carers give examples?

6. Did the student explain clearly what actions he/she would take/plan in relation
to their own practice following their time with the family? Provide an example?
7. Did the student do what he/she said they would in relation to their time with the family?
   Please give example?

8. Did the student display a caring and professional attitude/behaviour to the family?

9. What has been helpful to family carers about working with the student?
   What might the student have done differently?
10. Did the student thank the family for their time and effort spent on the placement?

11. **Comments:** Feel free to add anything you think is important to highlight

Thank you for completing this evaluation form

Please return to:

Jenny Whinnett
*PAMIS* Grampian Co-ordinator
Carers Centre
6 Arbuthnott Place
Stonehaven
AB39 2JA

Email: jenny.pamis@btconnect.com