Involving patient, service user, carer and public representatives

An information pack for staff

December 2014
Aim of this information pack

This pack provides practical information and guidance on how best to involve representatives. It will help you be clear about why and how you are involving them and help you support them in their role.

This pack is designed to provide you with the essential information you need to have a positive experience of involving representatives. If you find your project or group has more complex requirements, contact the Public Involvement Team within Corporate Communications on 01224 558098 (or internal extension 58098) or e-mail nhsg.involve@nhs.net

A similar information pack for patient, service user, carer and public representatives has also been produced. Please ensure that the pack is given to representatives involved in your project or group.

Both information packs are also available on the NHS Grampian intranet at:
http://nhsgintranet.grampian.scot.nhs.uk/depts/CorporateCommunication/PatientandPublicInvolvement/Pages/default.aspx

This information pack is also available in large print and other formats and languages upon request. Please call NHS Grampian Corporate Communications on 01224 558098.
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1. The basic stages of involving representatives – a quick reference guide

1.1 Definition of a public, service user, carer or public representative

Representatives all come from the community. Most of our representatives bring a patient, user, carer and public perspective and all will be working with NHS Grampian on a voluntary basis. A small number of representatives will come from an organisation such as a charity or a voluntary group and this may be on a paid or voluntary capacity.

1.2. Plan before involving representatives

• Identify the areas of work which require feedback and input from patients, service users, carers and the public.

• Decide on who and how many representatives to involve. This could be just patients or a combination of patients, carers, and the public. Remember to consider involvement of voluntary organisations which are appropriate to the work.

• Try and avoid having one representative attending a formal meeting with healthcare professionals. At least two representatives are recommended as they will act as informal support for each other.

• Be clear about what you want the representative to know about. As a minimum, this should include:
  - Group name and the group or project remit
  - Name and contact details of nominated staff who will act as the contact person for the representative
  - Outline of expected role/contribution of representative
  - Other useful details such as the name and contact details of the Chair and/or secretary, venue details, preference for papers in printed or e-mail format, and expenses claim forms.

Please contact the Public Involvement Team on 01224 558098 (or internal extension 58098) or e-mail nhsg.involve@nhs.net if you require more support with planning.

1.3. Methods of recruitment

Agree a plan with your team on how best to go about recruiting the representatives required. Here are some methods:
• **Personal contact/word of mouth** - if a patient or service user is required, it is regarded as appropriate for healthcare professionals who know them to ask if they wish to become involved. However, no one should be made to feel under any pressure to take part and should be reassured that their care will not be affected if they decide not to be involved. Any written approaches should be made in accordance with Data Protection guidelines, by a clinician known to the patient/service user.

• **Advertising** – create a flyer or poster for display in waiting rooms, clinics or wards or in community or primary care settings. Formal adverts or feature articles can be placed in newspapers, but please contact the Media Team within Corporate Communications first on 01224 558819 (or internal extension 58819) for advice. Editors of newspapers will have the final say on whether a feature article will be published. Please note that formal advertisements usually have to be paid for.

• **Random selection of clinic lists** – names chosen at random from lists of patients attending a clinic, service, or GP list. Please ensure that Data Protection guidelines are followed. Experience dictates that you will need to approach at least twenty patients to recruit one representative using this method.

• **NHS Grampian Public Involvement Network (PIN)** – is an established group which meets once a year and is made up of patients, carers and members of the general public who have an interest in health services in Grampian. PIN members can also be recruited for focus/discussion groups and projects. Contact is via the Public Involvement Team.

• **Public Partnership Forum (PPF)** – is a network of local organisations and individuals which will work in partnership with a Community Health Partnership (CHP) for the benefit of local communities. In Moray, PPF stands for Patient Public Forum.

• **Voluntary and community groups** – existing groups representing communities or special interests can be approached to provide a representative. If this is successful, it is recommended that clarity on who is covering expenses for the representative is obtained.

1.4. Other methods of involvement

As well as or instead of having representatives on your group or project, you may want to think about other methods of involvement. Each method has its own strengths and weaknesses. The method you decide upon will depend on what you want to find out, how many people need to be involved, what resources are available (including time), and the skills and knowledge you can tap into.
Methods of involvement can be found in the Scottish Health Council Participation Toolkit:

Guidance on planning a patient or carer experience project is also available on the NHS Grampian intranet:
http://intranet.grampian.scot.nhs.uk/foi/files/Improving_Patient_and_Carer_Experience.doc

1.5. Ethical considerations

Before undertaking any involvement or experience work it is recommended that any ethical issues are taken into account. Generally any service redesign work not requiring any identifiable patient information does not require ethics approval. As ethical requirements can change, it is recommended that you contact the Public Involvement Team on 01224 558098 (or internal extension 58098) or e-mail nhsg.involve@nhs.net for guidance.

1.6. Supporting representatives

An information pack for patient, service user, carer and public representatives has also been produced. Please ensure that the pack is given to people involved in your project or group. The pack can be found on the NHS Grampian intranet at:
http://nhsgintranet.grampian.scot.nhs.uk/depts/CorporateCommunication/PatientandPublicInvolvement/Pages/default.aspx

• Meet with people who have shown an interest. Discuss their interest and experience and their needs for support and training. This can be in the form of an informal interview. Discuss with them what their role will be. It will be helpful to also discuss what commitment and period of involvement will be required.

• If both parties are in agreement, write or e-mail the representative with a summary of what has been agreed.

• Nominate a staff member to be the contact person for the representative. This member of staff should ideally be the person to organise any induction and provide direct support and/or training for the representative.

• All representatives appointed must sign a confidentiality statement. This is provided as Appendix A on page 11. It is expected that this signed statement will be kept by the service requiring the involvement.
• Please note that a representative who will have direct and unsupervised contact with patients, carers and the public (e.g. helping out with surveys in clinics) must be issued with a name badge and must undergo a Disclosure Check before a start date can be agreed. See section 2 on page 10 for further details.

1.7. Expenses

Ensure other staff and the representatives are familiar with the NHS Grampian Expenses Policy for Patient and Public Representatives. Payment for expenses will come from the service requiring involvement unless otherwise agreed with the Public Involvement Team. The expenses policy and claim forms are available online: http://nhsgintranet.grampian.scot.nhs.uk/depts/CorporateCommunication/PatientandPublicInvolvement/Pages/default.aspx

1.8. Good practice for meetings involving representatives

When selecting a venue, consider the following:
• Access for people who use wheelchairs or who have limited mobility
• Access to toilet and disabled toilet facilities
• Acoustics – you may need a sound system or items that absorb sound in some large rooms or halls
• Any concerns about safety in or around the building (e.g. if meeting held after normal working hours)
• Accessibility to public transport routes and parking

Information sent out about the venue for the meeting should include:
• Details (full address and postcode) and a map of how to get there
• Details of parking, bus routes, train times
• Details of disabled parking and access
• For large complex buildings, consider an internal map for where the meeting is being held and directions to the meeting room (unless a meeting point in a reception area is arranged)
• A contact name and telephone number for any problems
• An expenses claim form

Timing:
• Give consideration to the timing of meetings. Preferably not too early in the morning unless this is preferred by the representatives involved
• You may not gather as many people during the day so you may have to consider an evening meeting
• If a meeting is held over a lunchtime you will need to consider providing food

Provide information about those involved in the group:
• Who else is going to be there – names and roles (use of photographic ID cards can be helpful for people to remember names)
• The organisation or department that they represent
• Their roles on the group
• Where applicable, a project structure

Papers and agendas for meetings:
The way in which paperwork for group meetings is organised can have a big influence on how easily representatives are able to contribute. Paperwork should be with the representative at least one week in advance.

It should be agreed in advance with the representative if they have a preference for hard copies by post or for papers to be sent via e-mail. If hard copies are preferred time must be allowed for sending papers in the post.

Things to avoid when preparing meeting papers:
• Use of jargon and technical phrases that are not explained
• Shorthand references and use of acronyms
• Assuming people know the policy background, latest reports etc.
• Assuming people understand about the structure of the NHS and Local Authority services

Things to remember:
• Public representatives should know arrangements for raising items at a meeting or putting items into the agenda.
• Ensure there is a procedure for letting representatives know if there has been a change to the meeting time or venue.
• Representatives attending their first meeting may feel nervous. Make sure there is someone to greet the representative, put them at ease and support them during the first few meetings.
• It is good practice to offer to meet with the representative before a meeting, to go through papers and answer any questions.

What to do at the end of the project or group:
• At the end of the project or group, it is recommended that there is an informal meeting with the representative/s to review their experience and impact of involvement, what worked well and any suggestions for improvement. A letter or e-mail of thanks at their end of involvement will always be appreciated by any representative.
1.9. What if it goes wrong?

Incidents

NHS Grampian has a duty of care to all representatives who volunteer their time. In the unlikely event of an incident occurring while a representative is working with us, this must be reported on the Datix Incident Reporting Form:

Appropriate support should be provided to the representative and the Public Involvement Team must be informed about any incident on internal extension 58098.

What if it goes wrong with the representative?

Involving people in the work of NHS Grampian will usually go smoothly. Most people become representatives for the right reasons. The best way of ensuring you have the right representative is to include them as part of a pilot phase to a project or to consider an initial appointment period followed by an informal review.

However, occasionally, someone may come along who is not right for the role. This may only become apparent after induction and they have started to attend meetings, or meet with other people. In the vast majority of cases, such problems can be sorted out satisfactorily and quickly through informal discussions.

If the problem is between the representative and their key contact person, then it is crucial that an additional member of staff is present at the informal discussion stage.

At the informal discussion stage, it is a question of:

- highlighting positive contributions
- finding out how the representative thinks their involvement is going
- explaining why the discussion is taking place
- outlining the problems
- looking at the reasons for behaviours
- agreeing a time scale for any changes agreed
- taking careful notes after the discussion

Very rarely it may be necessary to put things on a more formal footing. Problems are often best dealt with swiftly. To avoid tackling a problem only means that it gets increasingly difficult to deal with. Not dealing with a problem can also lower the morale of other representatives and paid staff.

It can be daunting to consider approaching a representative about their performance or behaviour and is not something to enter into lightly. Please contact the Public Involvement Team in the first instance on internal extension 58098. The suggested process for doing this is outlined in Appendix B on page 13.
2. A brief guide to Disclosure and the Protecting Vulnerable Groups (PVG) Scheme

The Scottish Government introduced the Protecting Vulnerable Groups (PVG) Scheme in February 2011. As a general guide, Disclosure Checks should only be requested for a representative if there is going to be direct and unsupervised contact with patients, carers and the public. This will normally be for a Standard Disclosure.

A request for PVG Scheme Membership should only be made in particular circumstances. Further detailed guidance is available at:

http://nhsgintranet.grampian.scot.nhs.uk/depts/CorporateCommunication/PatientandPublicInvolvement/Pages/default.aspx

3. National guidance for involving patients, carers and the public

The following national guidance documents have been developed to assist NHS Boards to involve patients, carers and the public in local healthcare services.

National Standards for Community Engagement (2005)


Guidance on Identifying Major Health Service Changes (Scottish Health Council, 2010)

Involving Patients, Carers and the Public in Option Appraisal for Major Health Service Changes (Scottish Health Council, 2010)

Public Involvement Team
Corporate Communications
NHS Grampian
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NHS Grampian Patient and Public Involvement
Confidentiality Agreement

In the course of your role as patient, carer or public representative with NHS Grampian you may have access to confidential or sensitive information.

For example, this may include hearing about a patient’s experience of a service, sensitive financial information, or problems and challenges within a particular service. Such information must be kept within the group or project you are working with.

On no account must information relating to patients be given to anyone other than medical or nursing staff who are directly involved with the care, diagnosis and/or treatment of patients.

If you are approached by any person or organisation (including the media) seeking information on any of the above matters, you must inform and seek advice from your contact person at NHS Grampian.

From time to time, information may need to be gathered or sought where a representative is representing a particular group or organisation, in order to gain feedback for NHS Grampian. If this situation arises, this will be explained and clarified by the lead or Chair of a group and/or by your contact person.

Please sign this agreement over the page. The agreement also includes permission for a service to pass on your details to the Public Involvement Team. Your details will go onto a database to enable the team to offer additional support and training opportunities.

Once signed your named contact person or a member of the Public Involvement Team will keep this in a secure place. Please ask if you would like to retain a signed copy for yourself.
NHS Grampian Patient and Public Involvement
Confidentiality Agreement

I hereby certify that I have read and agree with the above statement about the confidentiality of information. I will comply with the above requirements on confidentiality during the course of my involvement and after my involvement ends.

I give my consent for my details to be kept on a database held by the Public Involvement Team at NHS Grampian for the purpose of patient, carer and public involvement. I understand that I can withdraw my details from this list at anytime.

Name:

________________________________________________________________________

Address:

________________________________________________________________________

________________________________________________________________________ Postcode: ________________

Telephone: ______________________

E-mail: _____________________________________

Signed: __________________________________________ Date: ____________

Name of group/s I am involved in (if none, please leave blank):

________________________________________________________________________

________________________________________________________________________

NHS Grampian complies with the provisions and obligations of the Data Protection Act in the storage and retrieval of your personal information. Your information will not be disclosed or shared with any external organisations.

December 2014
Suggested process for when it may have gone wrong with a representative

Informal or oral stage
At this stage, it is a question of looking at the reasons for behaviours. It is essential to take careful notes and agree a time scale for changes. It is recommended that at least two members of staff are present, one of whom could be from the Public Involvement Team. A friend or relative may accompany the representative at all stages.

The main problem areas usually include:
- taking on tasks which go outside the agreed remit
- lack of respect for other people’s confidentiality, dignity, and differences
- breach of health and safety regulations
- not contributing at meetings despite offers of support
- persistent poor attendance and no apologies
- discriminating behaviour, e.g. regarding someone’s disability, race, sexuality, gender
- abusive, or other offensive language or behaviour
- arriving at meetings under the influence of alcohol or drugs, or other substance misuse.

It is also essential to:
- explain why the meeting is happening
- highlight positive contributions
- find out how the representative thinks their involvement is going
- outline the problems

Follow-up meeting
A further meeting will be needed if there is insufficient improvement in behaviour. At this meeting it is essential to take clear notes and to:

- find out what has gone wrong since the last meeting
- leave no doubt as to the serious nature of this meeting
- make sure that the representative fully understands what is happening
- agree time scales for improvement
- explain what will happen if there is no improvement

A follow up letter should be sent to the representative clearly stating what improvements are expected. It is important to try to keep the goodwill of the person involved, and also of the other representatives.
Dismissing the representative

In the unlikely case of gross misconduct, or if there is no improvement within the new time scale, the representative can be asked to leave. This must be put in writing to the representative within one week, giving reasons and details of the right of appeal. Any appeal must be received within 14 days of the date on the letter of dismissal. The representative will not be allowed to continue giving help pending any appeal.

Appeals

A right of appeal should be included at every stage and carried out within the agreed time limits. The representative (and a friend or relative if they wish), the nominated contact person of the representative and a senior manager should attend the appeal.