Chapter 5: How to involve patients and the public in dissemination and implementation of guidelines

Authors: Karen Graham,* Sara Twaddle, Carrie M. Davino-Ramaya and Loes Knaapen
*Corresponding author: Karen.Graham2@nhs.net

Aims of the chapter

This chapter provides guideline developers with advice on how to involve patients and the public in guideline dissemination and implementation. It is based on current practice from guideline developers, primarily the Scottish Intercollegiate Guidelines Network (SIGN), and suggests a wealth of examples of possible ways to involve patient groups in the dissemination and implementation of guidelines. It also provides information on the recruitment, skills, training and expected role of patients, carers and members of the public when participating in guideline dissemination and implementation activities.

Introduction

Involving patients and/or members of the public in the development of guidelines allows their views and experiences to complement the evidence and experience of health care professionals. When patients, carers or members of the public have been involved with the development of a guideline, they are in a good position to serve as informed advocates to communicate to others the importance of the evidence and the significant role that guidelines can play in making decisions about one’s own health care. Involving patients, public and carers in guideline dissemination is an additional critical step in successfully implementing clinical practice guidelines. Their input can be crucial in increasing awareness of the guideline, not only among patients and the public, but also among health care professionals. Their input is valuable to develop education materials, online resources and implementation tools that public and professionals audiences find useful, understandable and convincing. For clarity, we here present the role of patients and the public in three domains: 1. dissemination and 2. implementation of specific guidelines, and 3. raising awareness of guideline development in general. In practice, these three roles are best combined and intertwined, not kept separate.

Dissemination of guidelines

Dissemination of guidelines is about raising awareness about the existence and content of the guideline, to the public, patients and professionals. Patient organisations and charities are in a good position to promote guidelines at annual conferences and other regional and local events. For example, a patient organisation can promote a new guideline in their newsletter and at their annual member meeting, and provide the guideline on their website. Many patient organisations, charities and their networks include close connections with many health care professionals in their disease area. They can thus promote the guideline to professionals at events that are attended by both professionals and patient organisations.
**Dissemination to the public**

Involving individual patients and carers in media releases provides the best platform for their personal stories and can help to raise awareness of guideline recommendations. SIGN regularly involves patients and carers who have helped develop guidelines in media releases to highlight the importance of making diagnosis and treatment decisions based on the latest evidence.

**Dissemination to patients**

Patient organisations and charities can promote the guideline (and its patient version) in their newsletter, host it on their website and include it in the information packages provided to their members. At information sessions organised for patients and the public, they can distribute the patient version of the guideline and discuss how patients can use it to help them make treatment choices.

**Dissemination to professionals**

Patient organisations and charities also attend conferences aimed at (and organised by) health care professionals, to promote their own organisation and learn about new developments concerning their condition. In turn, many of the events and meetings organised by patient or user groups are frequently attended by health care professionals.

For example, the guideline on management of perinatal mood disorders (and its patient version) was launched at the Scottish Perinatal Mental Health Forum. This conference was organised by the Mental Health Network, a service user led organisation in the greater Glasgow area, and attended by service users and their families as well as (mental) health care professionals.

**Box 1. Patient organisation disseminating guideline to patients and professionals**

<table>
<thead>
<tr>
<th>Psoriasis Scotland Arthritis Link Volunteers (PSALV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Scottish charity Psoriasis Scotland Arthritis Link Volunteers (PSALV) provides the SIGN guideline on Psoriasis and Psoriatic Arthritis to its patient members. They promoted the guideline (and its patient version) on their newsletter, host it on their website and include it in the information packages provided to their members. At information sessions organised for patients and the public, they distribute the patient version of the guideline and discuss how patients can use it to help them make treatment choices.</td>
</tr>
<tr>
<td>PSALV also attends conferences aimed at (and organised by) health care professionals, such as the Scottish Dermatology Nurses annual conference. There, they raise awareness of the support and information their own organisation offers to patients and carers, but also distribute the SIGN guideline on management of Psoriasis and Psoriatic Arthritis.</td>
</tr>
</tbody>
</table>

**Implementation of guidelines**

Implementation of guidelines includes developing additional tools, documents or campaigns to encourage awareness and use of the guidelines. These tools can be designed either for the public/patients, or for professionals, and patients and public members can be involved in both the design and the promotion of such implementation tools. This can include web-based resources for health care professionals or patients to help disseminate and implement the guideline.
recommendations, for example, podcasts and video presentations. Or it can include the development of more- or less-extensive public awareness campaigns and strategies. Patients and the public can also be involved in developing patient versions of guidelines (see chapter 4) and the development of decision-making tools (see chapter 6). Once dissemination/implementation tools have been developed, patient and public members and organisations can help promote and distribute these tools, usually alongside the dissemination of the guideline itself, using dissemination strategies such as those in described above.

**Patient versions of guidelines**

Patient versions of guidelines give patients, carers and members of the public access to recommendations in guidelines. They can help people to understand the care and treatment choices available and allow them to play an active role in decisions regarding their own health. Patient versions of guidelines help patients to evaluate their own care, as they can monitor whether their own care is in line with the guidelines, and gives them the opportunity to discuss with health care professionals if they are not being offered recommended treatments. Providing patients with this information can help to change the behaviour of the health professionals caring for them. For example, the National Centre for Clinical Excellence in Norway produced a ‘recommendation card’ for patients that highlighted the ten most important recommendations so that patients and relatives had increased knowledge of what kind of assessment, treatment and follow-up to expect from their health care professionals. Such information is usually developed with the involvement of patients. For more information, see chapter 4.

**Development of web-based resources**

Often web-based resources are developed for health care professionals and patients to help with implementation of guideline recommendations. There are many examples of patients and public members being involved in the development of such implementation materials.

- The New Zealand Guidelines Group (NZGG) involved members from patient groups and lay members from NZGG’s Implementation Advisory Group in the development a web service to help with the recognition and early referral of autism spectrum disorder (ASD). They reviewed materials and provided input on design, and some of the video material is presented by a person with ASD, or their family and carers. [http://www.asdguideline.com/community](http://www.asdguideline.com/community)

- To help with implementation of the National Institute for Health and Clinical Excellence (NICE) guideline on self-harm, a podcast for patients and the public was developed. Within the podcast, a service user explains their experience of self-harm, access to services and harm minimisation. [http://guidance.nice.org.uk/CG133](http://guidance.nice.org.uk/CG133)

- As part of the NICE guideline on medicines adherence, a poster to inform patients and the public for use in waiting rooms and other health settings was developed. The poster provides a general template with the key messages from NICE in a clear and accessible format, which can be adapted for local use. The two patient/public representatives, who had been involved in developing the guideline, were also involved in developing this template. [http://guidance.nice.org.uk/index.jsp?action=download&o=43740](http://guidance.nice.org.uk/index.jsp?action=download&o=43740)
Public awareness-raising campaigns

Patient organisations and charities can be involved in using a guideline to develop education programmes for patients or people at high risk of a condition. Informing patients and the public about a condition and how best to prevent, diagnose, and treat it, can support the implementation of a guideline by encouraging patients to seek care in accordance with the guideline, and ensuring physicians treat patients in accordance with the (new) guidelines. In addition to being organised or co-developed by patient or charity organisations, patients can be involved in delivering and executing such education programmes. Box 2 provides an example of a successful patient-mediated education campaign based on a guideline.

The Breakthrough Breast Cancer Campaign is a non-profit charity organisation that developed guides to raise awareness and improve the availability of services for women at increased risk of breast cancer due to their family history. Based on NICE and SIGN guidelines, they develop guides for women on breast cancer diagnosis and treatment in the UK. [www.breakthrough.org.uk](http://www.breakthrough.org.uk)

Box 2. Patient-mediated awareness campaign

<table>
<thead>
<tr>
<th>Heart Heroes promoting the Community Heart Check</th>
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<tbody>
<tr>
<td>Individual patients can become involved in developing and delivering implementation support tools such as education programmes. The New Zealand’s Pharmaceutical Management Agency (PHARMAC) undertook a comprehensive project to implement the Cardiovascular (CVD) Risk Assessment Guidelines that were revised in 2009.</td>
</tr>
<tr>
<td>A small number of ‘Heart Heroes’ were selected to work with PHARMAC. These heroes were Maori men with heart conditions who were making lifestyle changes to better manage their heart disease. Their role was to talk about their personal journeys to other Maori men and to encourage others to learn more about their risk of heart disease. The ‘Heart Heroes’ attended local events such as sports or cultural events where ‘Community Heart Checks’ were set up that offered people free comprehensive cardiovascular risk assessments. The aim of the heart checks intervention was to create interest in heart health; inform people about their options for caring for their heart; empower people to start conversations with their doctors and nurses about heart health and to ask for regular heart checks; to create a ‘buzz’ within families and social groups to make having heart checks an easy and non-threatening thing to do.</td>
</tr>
<tr>
<td>Feedback received via the consumer survey indicated that reactions of people who had a Community Heart Check were positive and encouraging, indicating that people were interested and engaged in finding out about their level of heart health and what they could do for themselves and their families, including 82% who felt they would tell their friends to have a heart check. <a href="http://www.oneheartmanylives.co.nz/tane-stories.html">http://www.oneheartmanylives.co.nz/tane-stories.html</a></td>
</tr>
</tbody>
</table>

Raising awareness of guideline development (organisations) in general

SIGN also has established a group of patient and public representatives known as ‘Awareness Volunteers’, who help raise awareness of SIGN and their guidelines in more general terms. Their roles are diverse and include:

Contribute to advertising materials

- For example leaflets and posters, or media releases
Help SIGN exhibit at events, hospitals and conferences

- An information stand at the Royal Infirmary of Edinburgh was visited by approximately 200 people, mostly staff, who appreciated the volunteers’ presence and SIGN’s publications.

- The Bipolar Scotland conference, attended by 100 delegates was useful to get patients involved in SIGN’s work because it provided good networking opportunities and raised awareness of SIGN.

Give talks to patient groups and health care professionals

- Awareness volunteers provided an overview of SIGN and patient involvement to third year nursing students the University of Abertay who appreciated hearing the information from patients in their own words and liked the informal setting.

Encourage other groups to be aware of, and get involved in, SIGN’s work

- For example, community and user groups, such as Gartnavel diabetes support group where 20 members considered the talk worthwhile as most had not heard of SIGN, but now are interested in SIGN’s publications.

How to improve PPI in dissemination and implementation

SIGN takes a proactive role in supporting the implementation of its guidelines and in improving the implementability of its recommendations. Equipping patient and public members with the right knowledge at the onset empowers them to become effective partners in the dissemination and implementation process. SIGN has identified several areas where patient groups would have the biggest impact on guideline dissemination and implementation including publicising, monitoring, raising awareness, campaigning for change, and ensuring health care professionals are following guideline recommendations.

Recruitment

Patients and public members to participate in dissemination and implementation activities can be recruited in a variety of ways. First of all, patient and carer representatives who have participated in developing the guideline can continue to be involved in the next steps when the dissemination and implementation strategy and tools are development. When patients, carers or members of the public have been involved in the development of a guideline, they are in a good position to serve as informed advocates to communicate to others the importance of the evidence and the significant role that guidelines can play in making decisions about one’s own health care. For more advice on their recruitment, see chapter 2 of this toolkit.

Additionally, permanent groups, networks or ‘panels’ of patient and public members can be established to recruit from. In addition to the previously mentioned ‘Awareness Volunteers’ group, SIGN has a well established Patient Network which is a virtual network of patient groups, charities and voluntary organisations who are committed to assisting us with guideline dissemination and implementation activities. SIGN’s Patient Network members are alerted when new guidelines and patient versions are published and are asked if they can raise awareness of them and disseminate them through the various methods mentioned above, with the goal of reaching health care professionals, patients and members of the public in their networks. Members for these groups or
networks can be recruited via patient groups, charities, voluntary organisations and volunteer centres. Such groups should include diverse members, including those from equality and diversity groups, and various geographical regions.

**Informing patient and public participants about guidelines and their development**

To ensure patients and public groups are well-informed before participating, they are informed about guidelines and the role public and patient group members play in the development, implementation and dissemination of guidelines. Starting with the most basic information, we explain the role of the Scottish Intercollegiate Guidelines Network (SIGN) in writing guidelines that give advice about the best treatments that are available. We also explain that the guidelines are written in collaboration with doctors, nurses and other National Health Service (NHS) staff, and with patients, carers and members of the public. It is at this introductory point when we drive home the fact that our guidelines are based on the most up-to-date medical evidence written for NHS staff and patients to help make important decisions about health care; to make sure patients get the best care available, no matter where they live; and to improve health care across Scotland.

**Clarifying expectations**

It is important to provide as much detailed information as possible about the specific role of the patient, carer or member of the public. Expectations should be explicitly addressed in a formal recruitment packet. It is helpful to inform volunteers up front of the time commitment required as participants of a guideline dissemination/implementation team. It is good practice to offer potential volunteers the opportunity to attend an informal drop-in session to find out more about the role. In addition, a contact name and phone number could be provided for the volunteer to call when questions arise. An example recruitment poster is provided in this toolkit as appendix 5.1. Potential volunteers can complete an application form that allows them to share with guideline developers their reasons for wishing to join a dissemination group and to describe their relevant experiences for this type of work. An example application form is provided as appendix 5.2 in this toolkit. Potential volunteers should be asked to attend an informal interview with patient involvement staff to discuss how they might go about carrying out their role and to decide if they are suitable. An example set of interview questions is included in the toolkit as appendix 5.3. It is good practice to offer unsuccessful individuals feedback from the interview process and to make them aware of other patient involvement opportunities within the organisation that may be more suited for them, for example, reviewing draft guidelines.

**Skills required to join dissemination groups**

Patients, carers and members of the public should be fully trained to carry out their assigned role. The following characteristics however should be apparent in the individuals you interview including:

- Enthusiasm
- Time to commit to the work of the group (e.g. identify awareness-raising opportunities, preparing for and participating in awareness-raising activities)
- Good communication, presentation and teamwork skills.

**Training and support**

Patients and members of the public should receive full training to allow them to successfully undertake their role in dissemination groups. This can include:
• Information on the guideline development process and methodologies
• Practical tasks to develop communication skills and presentation skills
• Individuals should be given a named contact who can support them via email, telephone or face-to-face
• The opportunity to meet with patient involvement staff should be made available at various times of the year
• Individuals who are new to this role can be assigned a ‘buddy’ (a patient or member of the public already carrying out this role) to help them carry out their role in dissemination activities.

Resources
Resources at the organisational level required to successfully involve patients and members of the public in dissemination groups include:

• Staff time to recruit, train and supervise patient and public members
• Sufficient finances to reimburse out-of-pocket expenses including travel expenses, child care expenses and carer allowance
• Sufficient finances for publicity materials
• Possibly, financial compensation for patient and public representatives’ time and work. See chapter 1, ‘Valuing members—the problem of payment’ for a discussion of the importance and challenges of providing such compensation.

Conclusion
In conclusion patients and members of the public play an active role in guideline dissemination and implementation activities. Patient and public engagement ranges from involving them in the development of educational materials and implementation tools to raising awareness of guidelines with various stakeholders. The examples given in this chapter demonstrate how involving patients and the public has been successful and provides a useful guide to involving patients and the public in future dissemination and implementation activities.

References


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Appendix 5.1

Would you like to volunteer to work with SIGN to help them to get the latest up-to-date evidence-based health information to patients, carers and members of the public?

SIGN writes clinical guidelines for all NHS staff—including doctors, nurses, dentists, physiotherapists, occupational therapists—and also for patients. SIGN guidelines give advice on the best treatments that are available. We write them by working with NHS staff as well as with patients, carers and members of the public. The guidelines are based on the most up-to-date medical research evidence.

Patients, carers and members of the public play an important role in our work. Involving patients and carers in the development of our guidelines allows their views and their experiences to complement the evidence and the knowledge and experience of health care professionals.

SIGN has begun to produce patient information booklets which are based on our clinical guidelines. These booklets explain the recommendations in the clinical guideline; and help to make patients aware of the tests and treatments they should expect to receive from the NHS. We want to make sure that patients, carers and members of the public know about this resource and we need your help to do it!

We believe that patient, carer and public involvement at SIGN shouldn’t end when our guidelines are published. We are looking for (lay) volunteers to help raise awareness of SIGN’s work and patient involvement opportunities within their own communities/locality.

What would we ask you to do?

You would be a member of a group of 10-12 people. Tasks may include:

1. Actively identifying awareness-raising opportunities and advising the Patient Involvement Officer at SIGN of these
2. Helping SIGN to exhibit at events, giving talks to patient groups
3. Contacting local groups and clubs to encourage them to host awareness talks to help raise awareness of SIGN’s work (for example, Community Health Partnerships, community and user groups)
4. Identifying groups to distribute guidelines, patient booklets and information leaflets to and help them distribute to relevant groups they are involved with
5. Contributing to advertising materials such as leaflets and posters
6. Highlighting patient issues of concern which arise from awareness-raising activities.

You may also be asked to support lay representatives on guideline development groups who become involved in awareness-raising activities.
How much of your time do we ask for?

You are free to give as much time as you wish to SIGN. We do ask you to make sure you have the time to commit to at least two awareness-raising activities per year and a few hours per month.

What skills are required?

We are not asking for specific skills or knowledge as you will be fully trained to carry out this role. It will however help if you have some of the following:

- Enthusiasm
- Time to commit to the work of the group (e.g. identify awareness-raising opportunities, preparing for and participating in awareness-raising activities)
- Good communication, presentation and teamwork skills.

Expenses

We can’t pay you a salary but all travel expenses and other out-of-pocket expenses will be reimbursed, for example:

- Costs of travel to and from meetings
- Parking charges
- Child care.

What can you expect from SIGN?

- Appreciation and respect
- Safe working conditions
- Support
- Relevant information and training opportunities
- Information in a format that is suitable (e.g. large print, Braille or another language).

What training and support will you receive?

All Awareness Volunteers will be asked to attend a full-day induction and training day. The interactive training day aims to equip volunteers with the knowledge and skills necessary to carry out this role.

The Patient Involvement Officer will provide email and telephone support to members of the patient dissemination group. The group will meet with the Patient Involvement Officer and the Implementation Advisor at least once a year to identify problems, good practice and possible improvements.

A number of SIGN buddies are available to meet and support new patient, carer and public representatives who become involved with SIGN. They are available to meet face-to-face, by email or by telephone.
**Declaration of interests and confidentiality**

We ask everyone involved with SIGN to sign a declaration of interests form. This asks you about your personal and non-personal interests in commercial companies that might be, for example, involved in producing new drugs. We ask everyone involved in SIGN’s work to act as independently as possible. If you have significant personal interests that may conflict with SIGN’s work then we may ask you to withdraw from your work with SIGN. We also ask everyone to sign a confidentiality agreement to make sure they do not make any work of SIGN public until consultations and launches.

**How should you apply?**

You should complete the application form and provide a short personal statement detailing your reasons for wishing to become a SIGN Awareness Volunteer. You should also highlight any relevant skills and experience.

SIGN is committed to equality of opportunity and encouraging a diverse range of applicants. We ask applicants to complete an equalities monitoring return so that we can identify any equality groups that we have not reached. This is separate from your application and is not considered in the recruitment process.

All applications will be considered by SIGN’s Senior Management Team and the Patient Involvement Officer. Short-listed nominees will be invited to an informal interview on 3rd/4th October in Edinburgh or Glasgow with Patient Involvement staff.

We will be holding drop-in information sessions in Edinburgh and Glasgow to give you the opportunity to find out more about the role by speaking to staff and volunteers:

- Edinburgh, 6th September 2011 (1:30–3:30)
- Glasgow, 7th September 2011 (1:30–3:30).

If you would like more information or would like this information in another format, please get in touch with Karen Graham, Patient Involvement Officer, by phone at 0131 623 4740 or by email at karen.graham2@nhs.net.

Completed nomination forms and personal statements should be returned to Karen Graham at the address above by **Monday 19th September**.
Appendix 5.2

Application for SIGN Awareness Volunteer

Please complete this form to apply to be a SIGN awareness volunteer. If you have any questions or concerns about the form, please call Karen Graham, Patient Involvement Officer at 0131 623 4740 or email her at karen.graham2@nhs.net.

Contact details

Full name: 

Address: 

Telephone number (home): 

Telephone number (mobile): 

Email address: 

Nominating organisation (if applicable): 

Named contact from nominating organisation: 

Address: 

Telephone Number: 

Email address: 

Please return your completed nomination form to Karen Graham, Patient Involvement Officer, SIGN Executive, Elliott House, 8-10 Hillside Crescent, Edinburgh, EH7 5EA or to karen.graham2@nhs.net by Monday 19th September.
Volunteering with SIGN

Training

To become an Awareness Volunteer with SIGN, you must be prepared to attend a full day induction and training day on Thursday 20th October 2011. Please tick the box to indicate that you are willing to attend training. □

Which areas would you be able to volunteer in? (please tick all that apply)

- Within 20 miles of my home address only □
- Scotland wide □
- Ayrshire and Arran □
- Borders □
- Dumfries and Galloway □
- Fife □
- Forth valley □
- Grampian □
- Greater Glasgow and Clyde □
- Highland □
- Lanarkshire □
- Lothian □
- Orkney □
- Shetland □
- Tayside □
- Western Isles □

Please return your completed nomination form to Karen Graham, Patient Involvement Officer, SIGN Executive, Elliott House, 8-10 Hillside Crescent, Edinburgh, EH7 5EA or to karen.graham2@nhs.net by Monday 19th September.
Personal statement
(Please detail your reasons for wishing to become a volunteer and list any relevant skills or experience.)

Thank you for applying to be a SIGN awareness volunteer.

Please return your completed nomination form to Karen Graham, Patient Involvement Officer, SIGN Executive, Elliott House, 8-10 Hillside Crescent, Edinburgh, EH7 5EA or to karen.graham2@nhs.net by Monday 19th September.
Appendix 5.3

Awareness Volunteer Questionnaire (SIGN)

Candidate name: ________________________________

Vacancy reference: ______________________________

Panels: _______________________________________


### Personal Awareness

1. Tell us a little bit about yourself and your reasons for applying for this position.

2. From the role description what do you understand the role of the Awareness Volunteer to be and what personal qualities and skills do you have to bring to the role?
### Communication

<table>
<thead>
<tr>
<th>3. Within this post you would be expected to communicate with a variety of individuals varying from health care professional level to members of the public and patients. What experience do you have of working with a range of individuals?</th>
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</thead>
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<table>
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<tr>
<th>4. As part of an awareness-raising visit you may find yourself in some challenging situations, for example, patients and the public often find it difficult to accept SIGN's methodology. Can you tell us about a time when you had to use your communication and diplomacy skills to resolve a difficult situation?</th>
</tr>
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</table>
### Working with others/networking

<table>
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<tr>
<th>5. <strong>Team work</strong>—Being able to work as part of a team is important for this role. What qualities do you have that you would consider contribute to being an effective team member. Can you give us a positive example of being part of a team?</th>
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<tbody>
<tr>
<td>6. <strong>Networking ability</strong>—If a new guideline or patient version was launched there may be a requirement to increase the networks/sources of patients that these should be disseminated to. How would you go about creating a new network of contacts in these circumstances?</td>
</tr>
<tr>
<td>7. <strong>Engagement skills</strong>—Tell me about the steps you would take to make sure there is full participation and commitment from the right people to become involved in SIGN guidelines.</td>
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</table>
### Judgement and decision-making

| 8. You may be faced with situations which are quite emotive while visiting patient support groups or projects. Often patients find it difficult to accept why their particular issue has not been addressed in the guideline. How will you deal with a difficult audience and how will you ensure that you keep to the facts and apply objectivity? |
**INVITE QUESTIONS FROM THE CANDIDATE**

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<tr>
<th>0 - Inadequate</th>
<th>1 - Weak</th>
<th>2 - Acceptable</th>
<th>3 - Strong</th>
<th>4 - Exceptional</th>
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<tr>
<td>Much less than acceptable performance</td>
<td>Less than acceptable performance</td>
<td>Performance of a standard to do the job</td>
<td>More than acceptable performance</td>
<td>Outstanding performance</td>
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<tr>
<th>Behaviour</th>
<th>Question</th>
<th>Score</th>
<th>Comments</th>
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<td>Personal awareness</td>
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<td>Working with others/networking</td>
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<td>Judgement and decision-making</td>
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<td>Total</td>
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Interview Record

Title:       Post Ref.:       

Candidate:  Candidate. No:      

Date:       Time:       

PANEL DECISION:  OFFER ☐  HOLD ☐  REGRET ☐       

Signature:       Date:       

_______________________________  _____________  

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