



BC Cancer Agency

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Patient Engagement

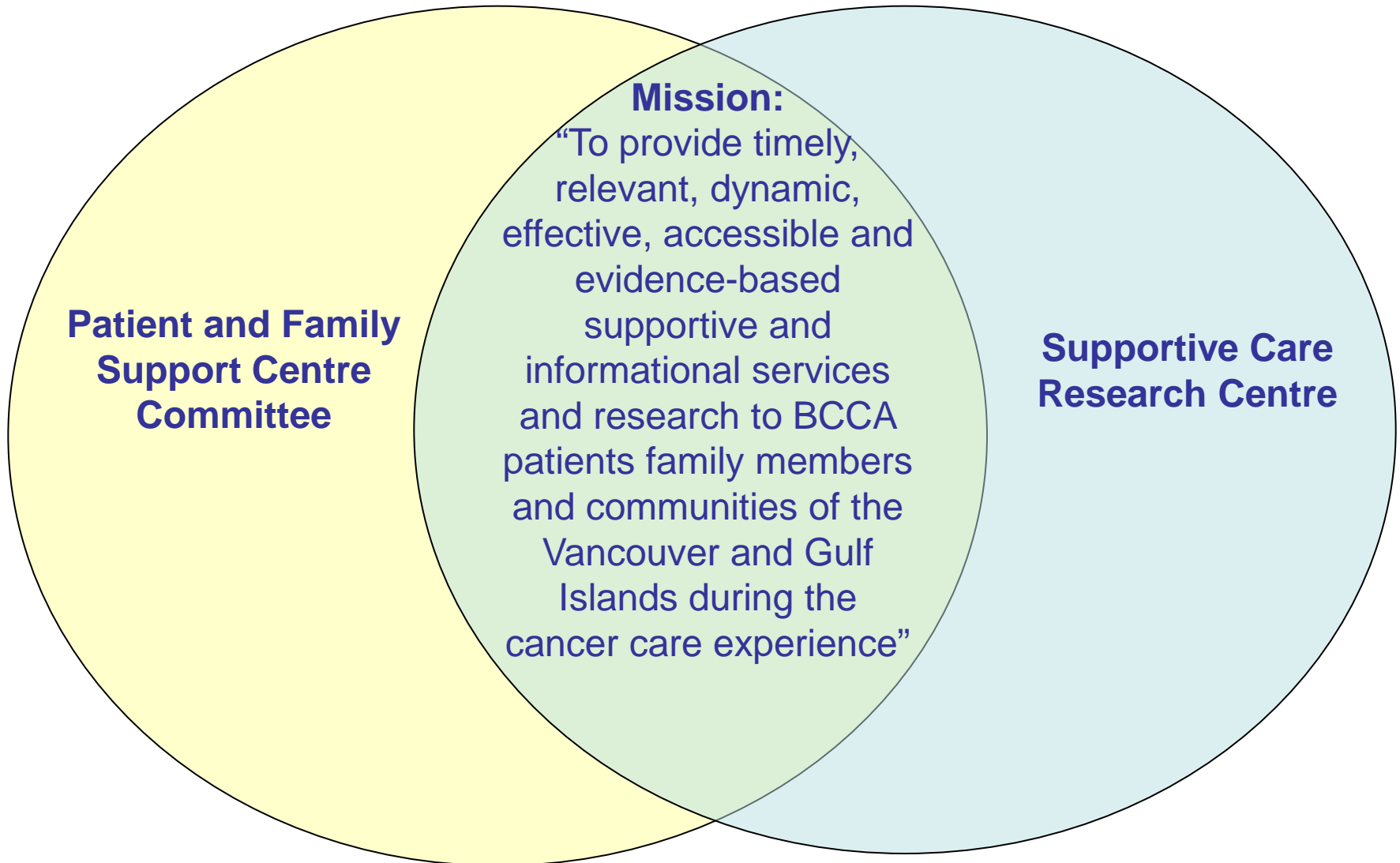
Vancouver Island Cancer Centre

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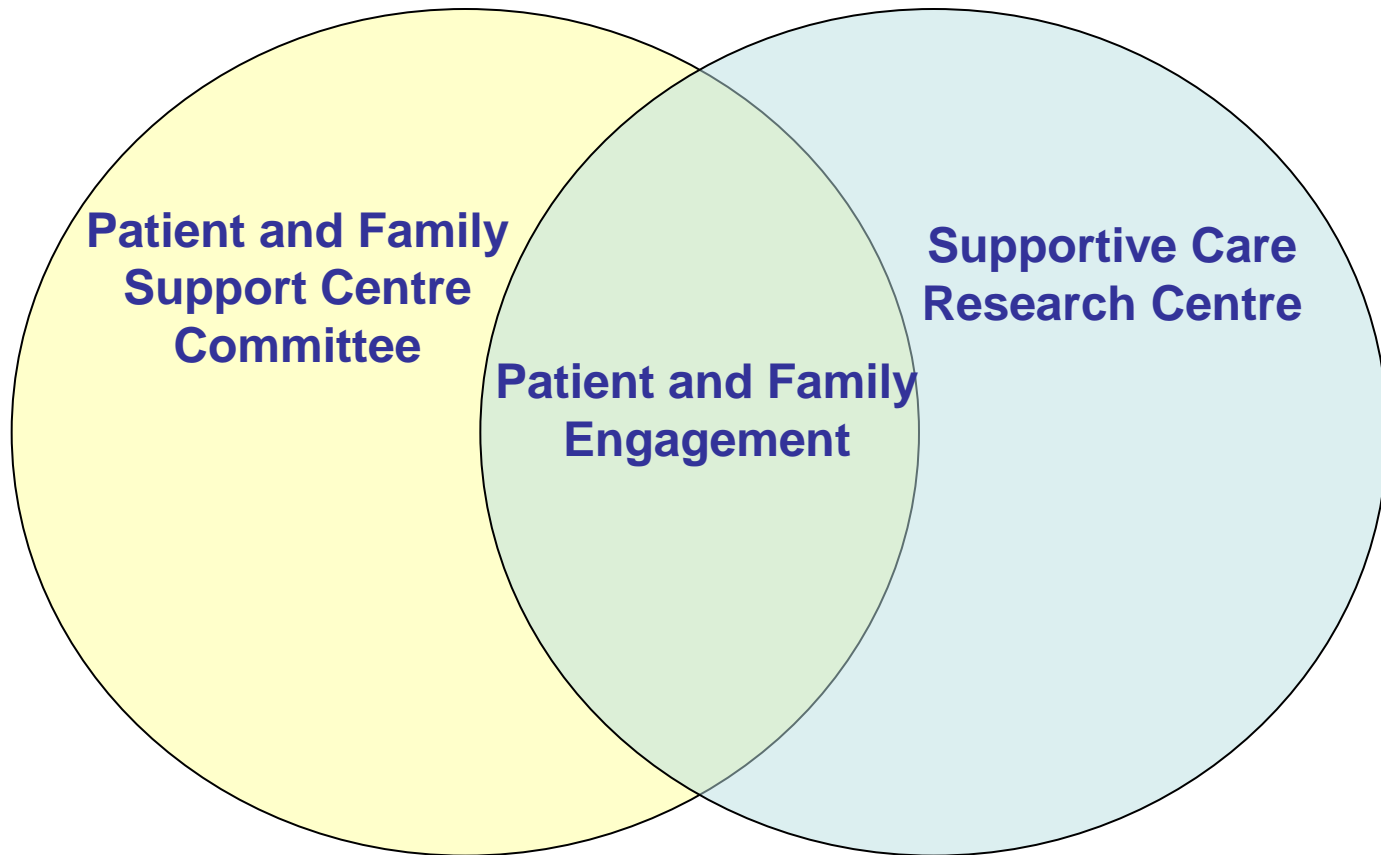
Aug 18, 2010

Alex and Jo Campbell Patient & Family Support Centre



Alex and Jo Campbell

Patient & Family Support Centre



Patient and Family engagement in the design, delivery and evaluation of cancer care, and in priority setting for and participation in research

Patient Engagement in Program Design

Lay Navigation Program

Representatives from:

- Community based cancer organizations
- Cancer support groups
- Centre based Patient Advisory Council

Keys to success:

- Involved from beginning with interdisciplinary team
- Provided orientation to project
- Sent materials ahead for review
- Provided abbreviation reference guide
- Balance of patient representatives and organizational representatives



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Patient Engagement in Program Design Advance Care Planning

Focus group recruitment from existing volunteers:

- Invited former/current patients
- Input needed to guide patient questions

Keys to success:

- Provided background information
- Diversity of participants

Opportunities:

- Review focus group intent with individuals prior to participation



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Patient Engagement in Program Design

Restorative Yoga Class

Representatives from:

- Volunteer network
- Community based cancer organizations
- Community based yoga programs

Keys to success:

- Involved from beginning with interdisciplinary team
- Provided orientation to project
- Sent materials ahead for review

Opportunities:

- Maintain project momentum and communication



Patient Engagement in Program Delivery

Volunteer Roles

Recruitment and Screening:

- One year post active treatment or loss
- Review of motivation and current health status

Keys to success:

- Opportunities for sharing their knowledge
- Position descriptions and orientation

Opportunities:

- Develop network of those interested in sharing their experience



Patient Engagement in Program Delivery

Education and Support Groups

Role of Patient Participant:

- Welcoming session participants
- Sharing personal experience as appropriate

Keys to success:

- Screened for role
- Position descriptions and orientation to role

Opportunities:

- Initiate role based on program need



Patient Engagement in Program Evaluation

New Patient Orientation

Project Plan

- Establish a design team including staff, patients, family members and community representatives to evaluate, revise and develop patient education materials.

Project Goals

- Improve patient preparedness for consultation with oncologist.
- Address informational needs of new patients during the latency between diagnosis and consultation with oncologist.



Patient Engagement in Program Evaluation

New Patient Orientation

Project Methodology

- Using Quality Improvement methodology and patient engagement, revise and produce a New Patient DVD and information booklet.
- Evaluate effectiveness of educational packages with the use of a patient-developed survey.
- Implement practice changes in response to patient feedback.



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Patient Engagement in Program Evaluation

New Patient Orientation

Practice changes

- New DVD
 - ✓ including chapters,
 - ✓ informal style narration,
 - ✓ content patient focused
- Mail out of DVD
 - ✓ new patient booking clerk process



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Patient Engagement in Program Evaluation

New Patient Orientation Survey

- Developing the survey
 - ✓ Patient-driven
 - ✓ Questions queried the goals of the project and sought understanding of any special population issues.
- Survey questions examined the following:
 - ✓ New patient preparedness for oncology consultation
 - ✓ Additional information the new patient was interested in
 - ✓ What format the new patient preferred information to be in.
 - ✓ Demographic details – geographic location & age.

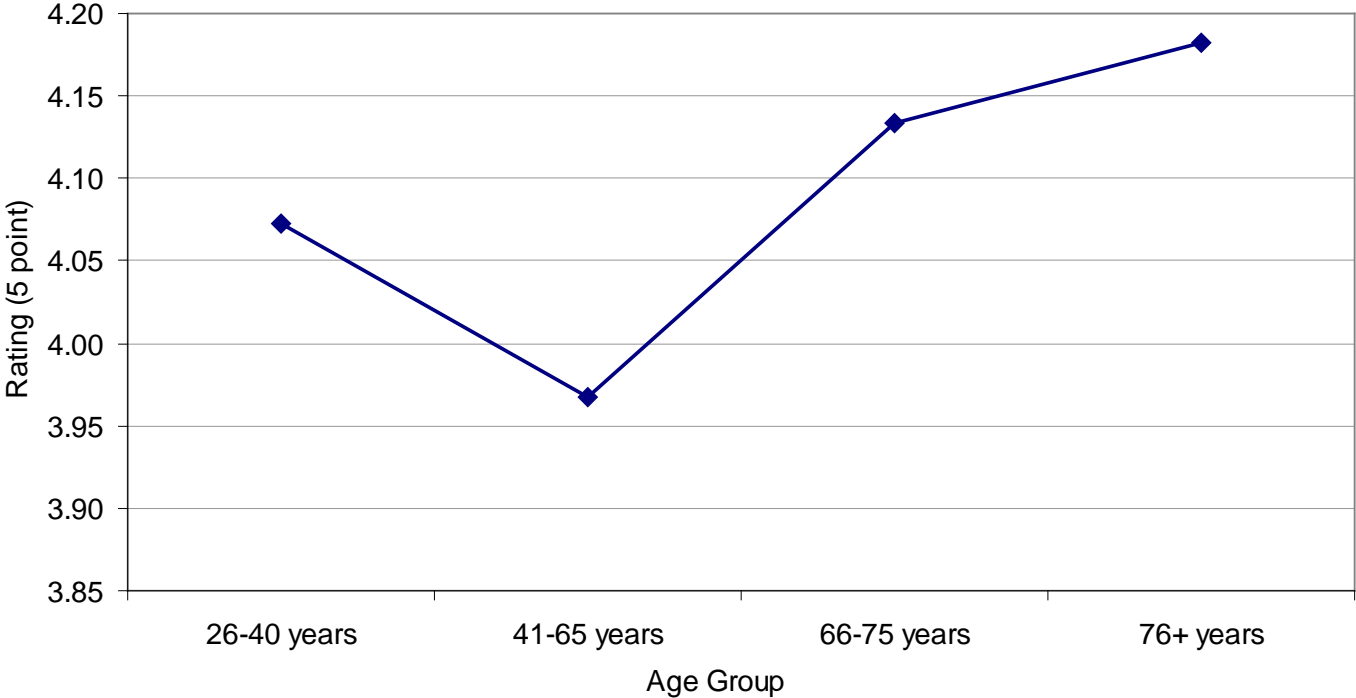


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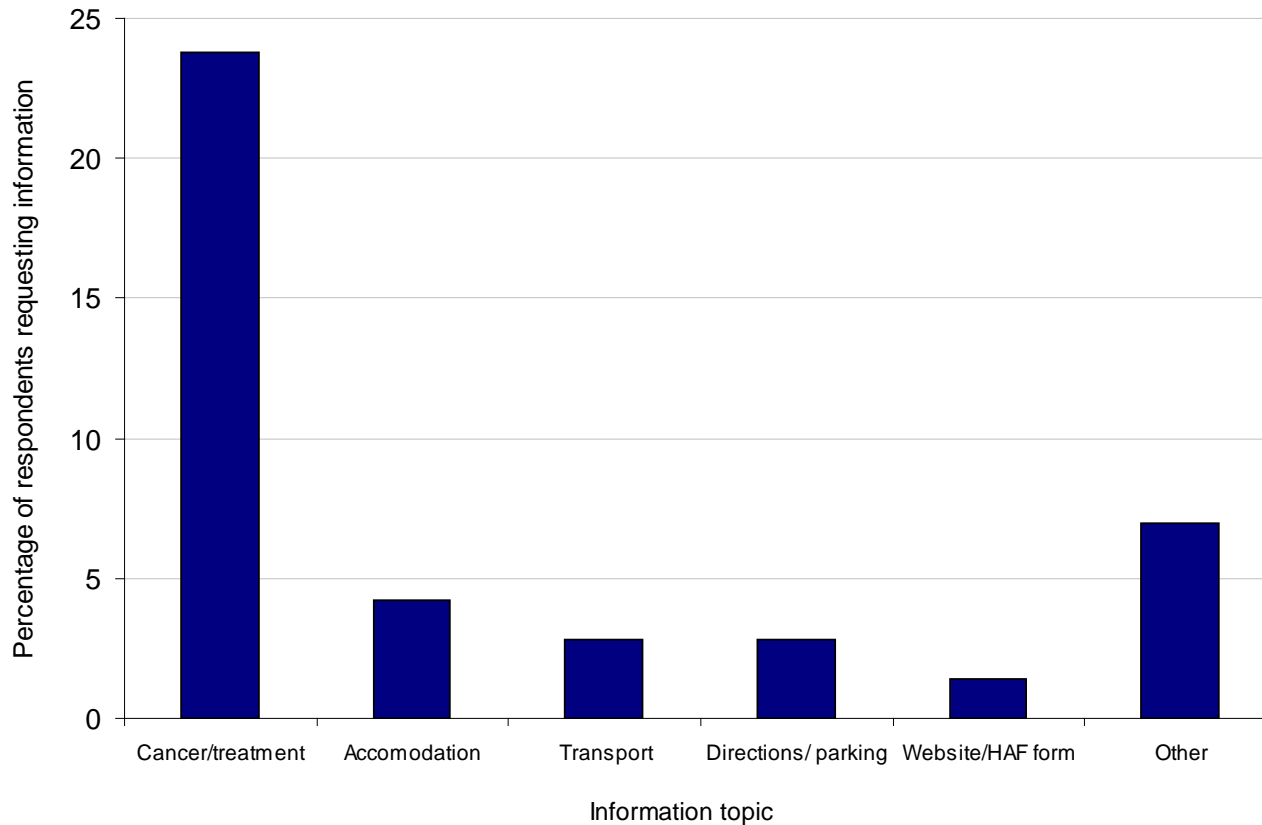
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Patient's Perceived Preparedness for Oncology Consult after Viewing the New Patient DVD



Patient's perceived preparedness for oncology visit by age group

Requests for Additional Information: Phase 1



Topics that patients requested more information about following distribution of New Patient DVD

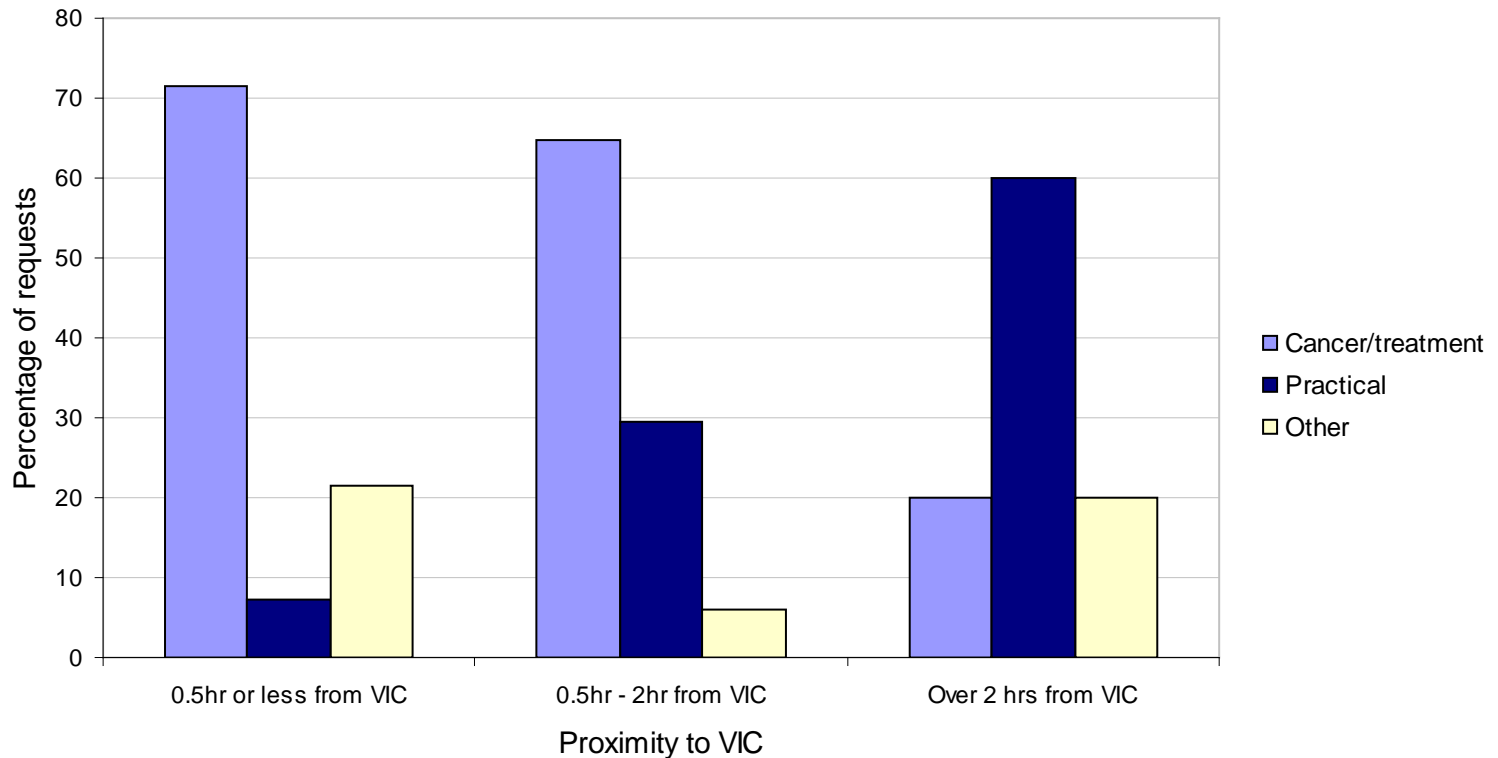


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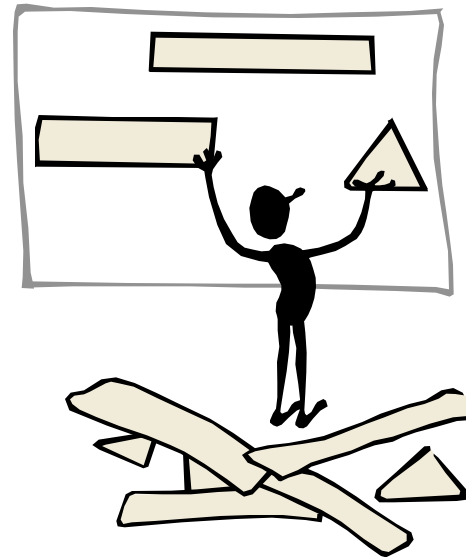
Information Requests by Patients from Differing Proximities to VIC



Distribution of requests at differing proximities to VIC (DVD only)

Patient-Driven Improvements: Revisions following Phase 1

- Mailing out the Health Assessment Form.
 - ✓ Improvements for both patients and clinicians.
- Design team reactivated to develop DVD accompaniment guide



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Patient Involvement – New Patient Booklet

- Patient representatives on committee
- Patient's network engaged for input
- Patient surveys
- Evaluated draft
- Changes incorporated

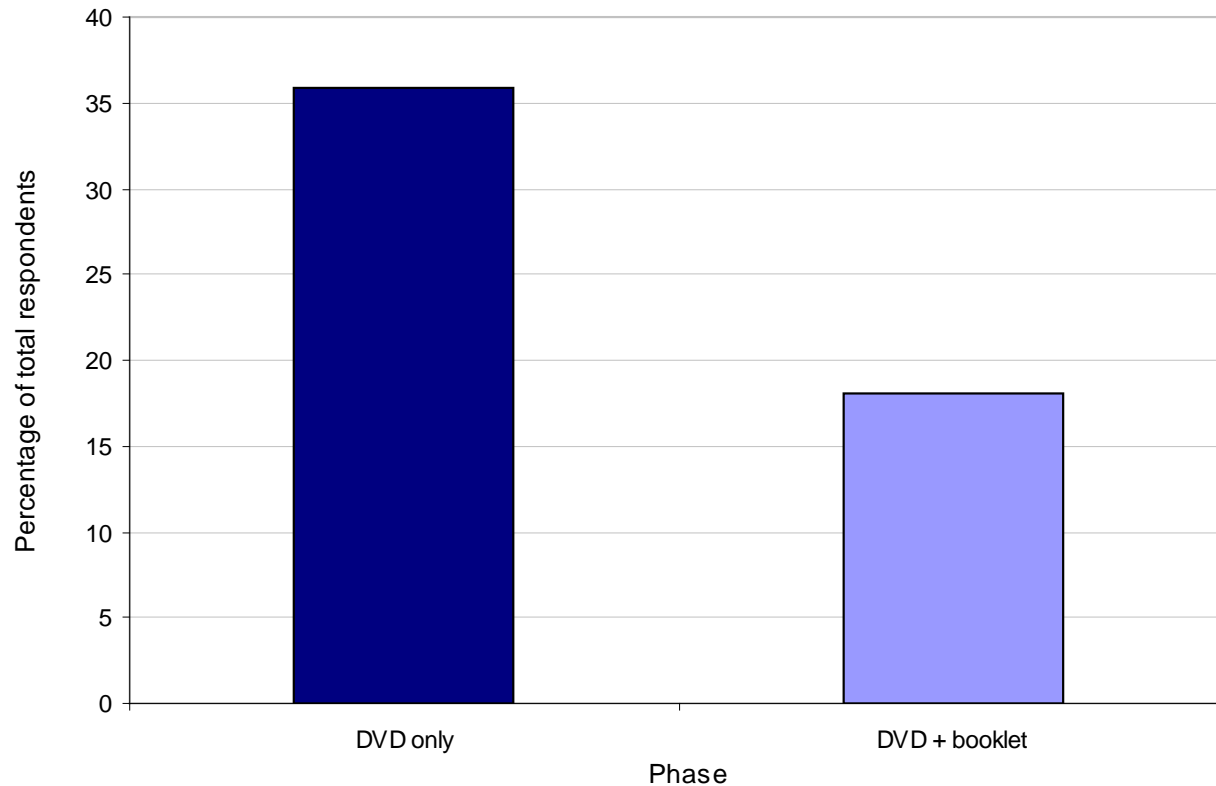


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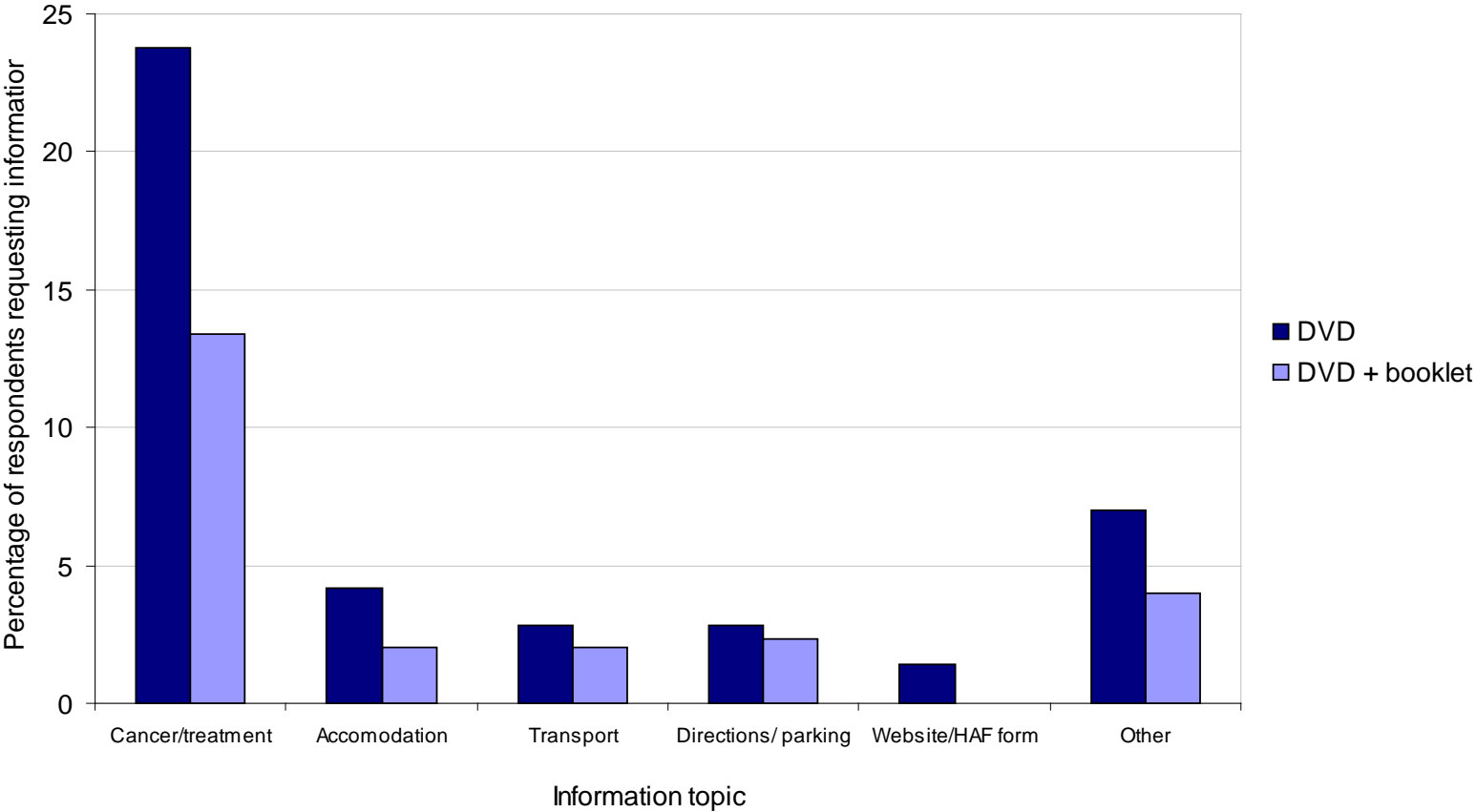
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Total Information Requests: Phase 1 versus Phase 2



Percentage of patients requesting information following DVD distribution and DVD + booklet distribution

Requests for Additional Information



Topics that patients requested more information about after DVD and DVD + booklet distribution

Patient Engagement – Future Considerations

- Provide clear expectations and boundaries for the role
- Offer training and orientation to the role
- Establish organizational point of contact
- Engage patient/family participants at the beginning
- Reference and background material best sent ahead of time
- Share feedback and results



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Patient Engagement – Success Measures

- Broad representation
- Meaningful input
- Participation valued
- Increasing opportunities



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