Remote consultations in cancer genetics: a review of Prince of Wales, ACT and Wollongong

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Acknowledgements

- Genetic counsellors ACT, W’gong, POWH
- Admin staff at POW, ACT, W’gong
- Telehealth SCH - help
  - Dr Richard Cohn
  - Hayley White
  - Melissa Dax
Outline

- Background
- Patient seen
- Evaluation
- Savings
- Hiccoughs
- Conclusions
Background

- Clinical Cancer genetics now part of standard multidisciplinary cancer care
- Requires team - genetic counsellor
  - cancer genetics clinician
  - admin support
- Only 6 NSW Clinicians with expertise
- Need to maximise availability
Background

Genetic testing in cancer

- **Mutation search** - no mutation found does not mean no mutation present in breast and bowel families not all causative genes identified yet

- **Predictive test** – once family mutation found can test unaffected members Very accurate
Background

- Telemedicine facilities available since 1999,
- Used for cancer genetics since 2000
  - Initially max 3 patients/session every 2-3 mth ACT
  - Wollongong service commenced Dec 2005
  - Now ACT & W’gong each up to 10pts /session/month
- Access to services in ACT & W’gong **only** via Telehealth – otherwise trip to Sydney
- Clinical Cancer genetics now part of standard cancer care access becomes important
849 referred

658 registered POW

435 patients seen on 539 occasions

189 discussed no further FU

223 discussed, not yet seen, or seen POW

98 tested, 23 seen POW
57 waiting appointments
45 managed by letter
Canberra Telehealth team
NUMBER of CASES by year

- 2001: 14
- 2002: 26
- 2003: 68
- 2004: 91
- 2005: 130
- 2006: 111

ACT and WC cases from 2001 to 2006.
Services by year for Illawarra

- **Clinics**
- **Telehealth**

Year | Clinics | Telehealth |
--- | --- | --- |
2000 | 15 | 0 |
2001 | 19 | 0 |
2002 | 22 | 0 |
2003 | 36 | 0 |
2004 | 34 | 0 |
2005 | 47 | 7 |
2006 | 49 | 79 |
NUMBER of tests

2001: ACT 10, WC 0
2002: ACT 14, WC 0
2003: ACT 43, WC 0
2004: ACT 58, WC 0
2005: ACT 83, WC 12
2006: ACT 58, WC 42

ACT and WC bars for each year.
Rural patients

- ACT - 31% pts - rural postcodes all yrs
  - 69% - metropolitan postcodes

- Wollongong
  - 29% rural 2005
  - 25% rural 2006
  - 71% metropolitan 2005
  - 75% metropolitan 2006
Evaluation in 68 ACT pts seen 2003

61 responded, 7 did not
Likert scale - 14 questions
Q. I felt I benefited from the video-conference session

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<th>neither</th>
<th>agree</th>
<th>Strongly agree</th>
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<td>5%</td>
<td>11%</td>
<td>84%</td>
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Strongly disagree: 5%
Neither: 11%
Agree: 84%
Strongly agree: 5%
Q. I would use again

- 98% agreed/ strongly
- 0% disagree/ strongly
- 1.6% neither

- 85% Strongly agree
- 13% agree
- 1.6% neither
- 0% disagree
- 2% Strongly disagree

Evaluation in 68 ACT pts seen 2003
Evaluation in 68 ACT pts seen 2003

Q. Videoconference session saved me time

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Evaluation in 68 ACT pts seen 2003

Q. Videoconference session saved me money

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<td>3.3%</td>
<td>5%</td>
<td>14.8%</td>
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Evaluation in 68 ACT pts seen 2003

Q. I would prefer to see the Dr face to face

48% disagree/strongly disagree
10% agreed/strongly agree

90%
Savings estimates

**Specialist** - saved 78 Canberra & 14 Wollongong trips

**Patients** – saved 465 Canberra and 71 W’gong trips

**Mileage**
- Canberra – 465 trips x 600km (?) 66c/km = $184,140
- Wollongong 71 x 200 (?) x 66c = $9372

**Patient time**
- minimum 7 hours travel Canberra (3255)
- 3 hours (217) W’gong

**Lost earning** unquantifiable
Health Care Savings

- Predictive genetic testing allows the 50% without the mutation to avoid unnecessary screening.
- 68 negative predictive tests
  - 36 don’t require early breast screening or risk reducing removal of ovaries and tubes
  - 16 don’t require annual colonoscopy
  - 17 don’t require other annual screening
- Predictive test requires identification of family specific mutation from an affected relative.
- This may not occur if trip to Sydney required.
Hiccoughs

Technical
- Major headache until upskilled
- Machine trouble (old machine in Canberra now giving trouble)
- Wollongong- No glitch at all with new machine in 98 consultations to date

Other
- 4/435 requested Face to face.
- 6/435 (1.4%) needed face to face after Telehealth.
Conclusion

- Remote cancer genetic consultations are acceptable to the vast majority of patients
- Saves time and money for patient, clinician and health system
- Allows access to cancer genetic services to greater number of patients
- Reliable equipment and experienced counsellor with patient essential for successful service
Wollongong Telehealth clinic
Five of 435 (1%) were difficult consultations where the medium \textit{may} have played a part.

- mutation +ve result person not previously seen by GC/CG,
- family dynamic where 3 generation, differing opinions
- unable to physically examine in rare syndromes
- 25 yr old wanted PM but no mutation in family
- affected wanted PM but no mutation found - grief