Improving health in Aboriginal and Torres Strait Islander women with Polycystic Ovary Syndrome – Challenges in Research Implementation

Monash Centre for Health Research and Implementation, A collaborative partnership to drive health care and public health improvement
School of Public Health and Preventive Medicine Monash University

Dr. Jacqueline Boyle
Disclosure

- NHMRC – fellowship
- Jean Hailes – NFP womens health
- Pfizer – Global advisory board 2014
- Member of the Polycystic Ovary Syndrome Australian Alliance
Outline

- Polycystic Ovary Syndrome (PCOS): An exemplar engagement and translation project
- The implementation research cycle
- Challenges and facilitators to implementation of evidence based health care for PCOS in rural and remote communities
Why does PCOS matter?

- Most common endocrine condition in women
- Diagnostic criteria include:
  - Oligo or anovulation
  - Hyperandrogenism (biochemical or clinical)
  - Polycystic ovaries on ultrasound
- Exclusion of other aetiologies
Polycystic Ovary Syndrome

Genetics

Lifestyle

Hormonal changes

↑ Androgens

↑ Insulin

Ovarian follicles
Anovulation
↑ Oestrogen

Hirsutism
Acne

Diabetes
Metabolic syndrome

Menstrual disturbances
Sub fertility

Cardiovascular risk

Psychosocial issues: body image, self esteem, depression, anxiety

Why does PCOS matter?

- Economic: Costs estimated at $800M/year
- Timely diagnosis aids prevention and management
- Key to prevention: optimal lifestyle from early in life
- Optimising mental wellbeing and QoL
The Research & Implementation Cycle

- Stakeholder partnership, formative research, framing problem, priorities, scoping
- Scale-up, evaluation and ongoing refinement
- Evaluation of health and economic outcomes
- Evidence informed implementation research
- Knowledge synthesis
- Implementation informed co-designed research & knowledge generation
- Knowledge dissemination, translation and exchange

Evidence informed implementation research
Framing the issue

- Highly prevalent
  - 10-12 % with ~68% not previously diagnosed (March et al 2010)
  - 15% -21% (Boyle et al 2011 MJA, Davis et al)
  - Increases with increasing BMI

Framing the issue

- Many delay in diagnosis, see a number of doctors, lack of information (Gibson-Helm et al 2014)
- Name is historical and misleading (Teede et al 2014)
- Clinical practice inconsistent, Primary care need support (Cussons et al, Teede et al 2014)
- Lack of focus on lifestyle management for weight gain prevention and weight loss (Teede et al 2011, Moran 2009, 2011)
- Psychological issues under-recognised (Deeks et al 2011, Moran et al 2012)
- National stakeholder workshop
Knowledge synthesis and implementation informed research

- National evidence based PCOS guidelines for diagnosis and management
  - Funded by federal government
  - National coalition: Polycystic Ovary Syndrome Australian Alliance.
  - Importantly consumers integrally involved through POSAA
  - Approved by the NHMRC
  - Commended by NIH, contracted by WHO
Evidence based guidelines

- Challenges in diagnosis and management
- Interdisciplinary model of care
- Assessment of emotional wellbeing
- Assessment of cardiometabolic risk
- Lifestyle management of PCOS
- Management of infertility:
  - Lifestyle
  - Pharmacological
  - Surgical
Implementation – an iterative process

The Change Process

Community Wide Strategy

Implementation Plan

THEN A MIRACLE OCCURS

Achievement

Self-sufficiency, "good citizens" healthy community

GOOD WORK, BUT I THINK WE NEED JUST A LITTLE MORE DETAIL RIGHT HERE!
Knowledge dissemination and exchange

- Publications: report, peer reviewed publications including international
- Presentations:
  - regional, national and international >6000 HPs
  - Consumer information sessions
- Consumer information: POSAA, Jean Hailes for Women’s health
- Information for Aboriginal and Torres Strait Islander women,
- Indigenous Health InfoNet,
- Website (~26,000 downloads), Webcasts (RHEF)
- Podcasts

PCOS Australian Alliance
Jean Hailes

Polycystic ovary syndrome

GP Tool

www.managingpcos.org
Challenges for Implementation of Evidence based guidelines

- Screening for diabetes and impaired glucose tolerance
- Interdisciplinary model
- Lifestyle management
- Screening for psychological wellbeing
Research Informed Implementation

- Melbourne PCOS clinics, community, hospital
- Adelaide PCOS
- Thursday island: based in primary health care

Specialists:
- Endocrinologist
- Gynaecologist
- Dermatologist

Allied Health:
- Psychologist
- Dietitian
- Exercise Physiologist

Reputable education sources and consumer support group:
- Jean Hailes: www.jeanhailes.org.au
- www.managingpcos.org.au
- POSAA: www.main.posaa.asn.au

General Practitioner:
- Central to ongoing care and co-ordination

Patient central to care and holds management plan
Evaluation of outcomes in the Torres Strait

Thursday Island

Primary Health Care service
Service with GP, women’s health nurse and dietician
Women visit depending on need
# Results

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>89</td>
</tr>
<tr>
<td>Cardiometabolic screening performed</td>
<td>50</td>
</tr>
<tr>
<td>Cardiometabolic screening ordered</td>
<td>78</td>
</tr>
<tr>
<td>Emotional screening</td>
<td>100</td>
</tr>
<tr>
<td>Lifestyle management</td>
<td>89</td>
</tr>
<tr>
<td>Infertility management</td>
<td>100</td>
</tr>
</tbody>
</table>
Exploring barriers to implementation

- Health services
  - transport
  - remembering appointments
  - length of appointments
  - challenges screening if no service available
  - information to women
- Sustainability of service
  - an “avalanche” of women
  - costs, staff
- How to implement healthy lifestyle Systems – food costs, adapting food, exercise
What worked and recommendations

- Dietician and goal setting
- Appreciated the time
- Fertility needs addressed
- Need to work with young women – prevention
- Support Groups, resources
- Clear plan and monitoring
- Determine ongoing financial support and allied health, Torres Strait Islander health care practitioners
Where to now?

- Centre of Research Excellence 2014, focus on Indigenous
- Incorporation into Adult Health Checks/ Well Women’s Checks in the Top End, Northern Territory
- Community health initiative in Melbourne to improve health service delivery for Aboriginal and Torres Strait Islander women
- Adelaide services being established
- International uptake of guidelines and PCOS clinic model
  - Europe, Singapore, WHO
Acknowledgements

- Consumers with PCOS
- Health Professionals
- Stakeholders
- NHMRC
- Department of Health
- Jean Hailes Foundation
- POSAA
- Thursday Island clinic and participants
- Members PCOA Australian Alliance