

Cairns 2013 InSiGHT meeting

- Response to directly approaching individuals at risk of inherited colorectal cancer: Experience of the NZ Familial Gastrointestinal Cancer Service
- Initial contact by letter
- Sent an appointment to discuss syndrome, health implications, offer endoscopy surveillance coordination

2013 conclusions

- 110% increase in surveillance programme participation
- Highly acceptable with no privacy or legal issues raised

Purpose

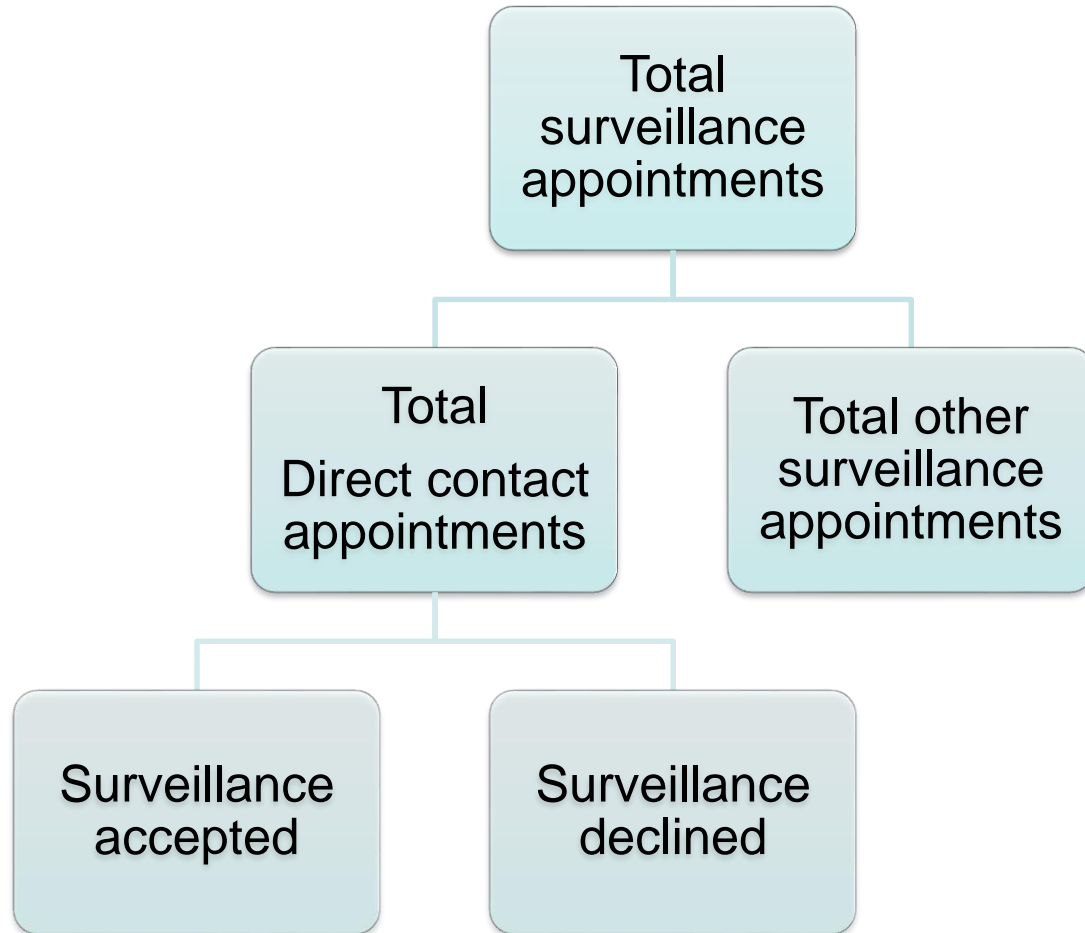
- To review if the 2012 increase was consistent over the following five years

Methodology

- Clinical Database search
- Jan 2013 – Dec 2017 at risk relatives of surveillance age, identified by family contact form from:
 - Lynch syndrome – first degree relatives (FDR)
 - Presumed Lynch syndrome* - FDRs and 25% risk
 - Syndrome X - FDRs

*Presumed Lynch – families awaiting mutation results or no mutation identified dMMR/MSI-H

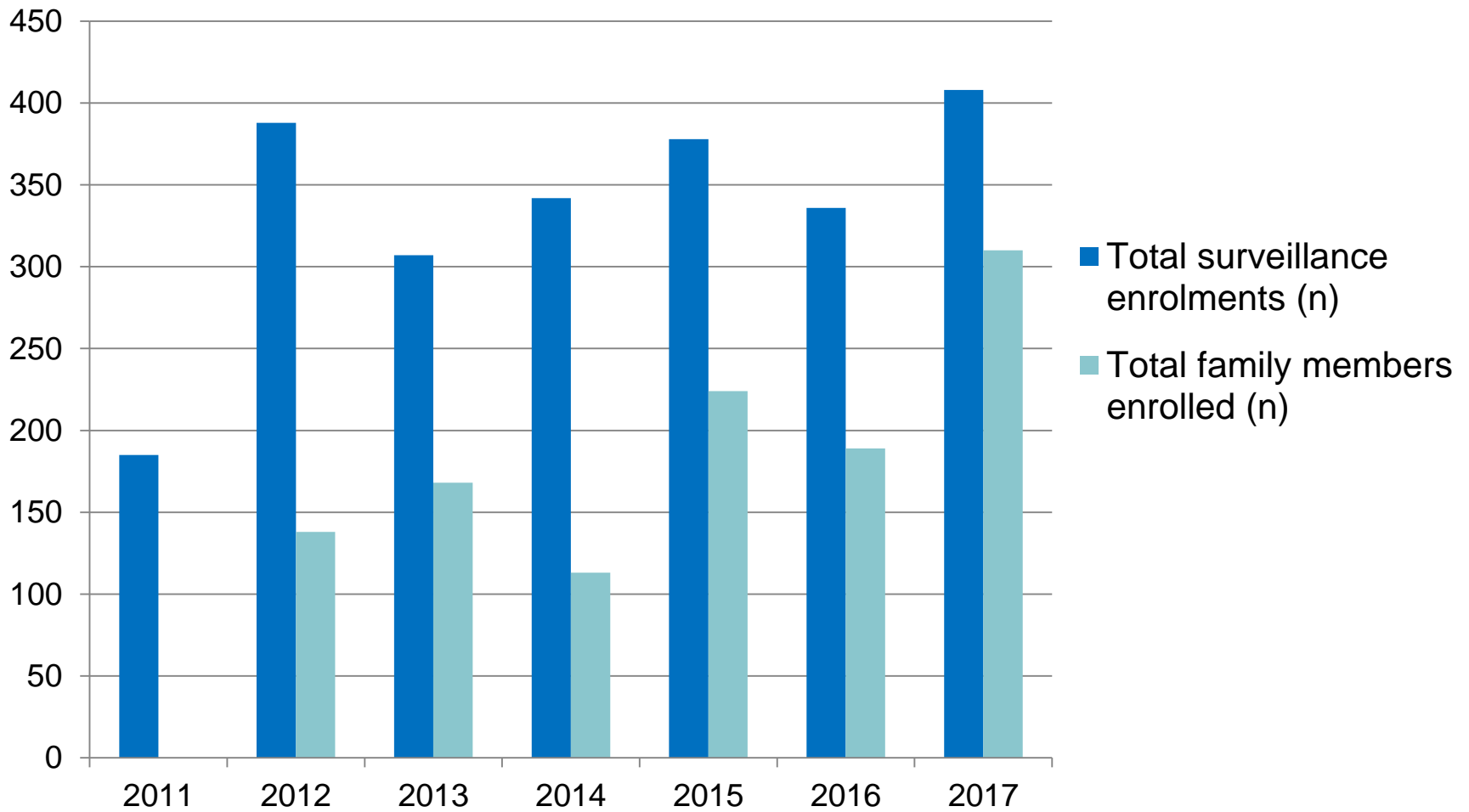
Methodology



Outcomes

Years	Total surveillance appointments	direct contact appts accept surveillance n (%)
2011	185	
2012	388	
2013	307	168 (55%)
2014	342	133 (33%)
2015	378	224 (59%)
2016	336	189 (56%)
2017	408	310 (76%)
Declined surveillance programme 2.5%		

Yearly Surveillance Enrolments



Direct contact

- Average year on year increase 20% in surveillance programme since 2012
- 56% of enrolments from direct contact
- 1024 individuals who may not otherwise been informed of their cancer risk

Pros

- Significant increase in surveillance participation by direct contacting
- Highly valued by families

Cons

- Workload increase
- Static funding
- Only NZ family members
- Decline rate not understood

Thanks!

Familial Gi Cancer Service staff

Auckland: Kirsten Craddock, Varnika Vijay, Rebecca Wang, Maggie Ow, Rachael Bergman, Nathan Atkinson, Susan Parry

Wellington: Ruth Wickens, Ben Griffiths, John Keating

Christchurch: Maxene Kiesanowski, Anita Barnett, Teresa Chalmers-Watson, Chris Wakeman

Administrators: Vici Angelou, Noeline Lyman, Kathy Isaacs, Suzanne O'Connell, Dolly Adams, Deidre Davey

Data Manager: Fiona Honeyman

Operations Manager: Rachelle Caverhill-Evans

Patrick Lynch