

DATA SUPPLEMENT

Methods

Education and training

A qualitative assessment of current FH medical management at each of the 15 research practices was undertaken prior to study commencement. This was followed by upskilling sessions on the research process for participating GPs, practice nurses (PNs) and practice managers (PMs) at each practice. This involved presentations, questions and answers on FH, including prevalence, diagnosis, and familial aspects including need for cascade testing of close relatives, treatment and follow-up.^{1,2} The investigation team (TB [WA], CHeal [QLD], JR [TAS], GG [VIC], CHespe [NSW] plus state project managers) undertook location visits to each of the 15 practices at least twice during the study.² All visits included re-enforcement of background information on FH, the proposed method of care protocol, the process of consenting patients and data to be collected. Practice GPs, PNs and PMs had the opportunity for one-on-one consultations with state GP clinical leads (TB [WA], CHeal [QLD], JR [TAS], GG [VIC], CHespe [NSW]) and research team lipid specialists (DS [NSW] and GW [WA]) at each stage of the research protocol allowing for specific discussion of individual patients as needed.

Electronic screening and clinical assessment

The study commenced with application of TAR-B-Ex to the practice EHRs to identify patients already listed as having FH and also potential high-risk, undetected patients at the practice. Medical record review of these patients was then undertaken by trained GPs and practice staff. Following manual review, patients confirmed as high-risk were contacted and invited to attend for clinical review and medical record update with their GPs. A detailed assessment of family and personal history and physical examination was undertaken at this review. A clinical ASCVD event was defined as the presence of myocardial infarction, angina pectoris, percutaneous coronary intervention, coronary artery bypass grafting, ischemic stroke,

transient ischemic attack, and/or peripheral artery disease. Using the DLCNC score, patients scoring 6 or above (probable/definite FH) were diagnosed as phenotypic FH. Genetic testing did not form part of the study protocol.

A pragmatic approach was adopted where patient records showed lipid medications had been prescribed but serial lipid profiles suggested non-adherence. Where patients had been on lipid medications at first contact and profiles suggested compliance, TARB-Ex's algorithmic correction factor estimated the approximate un-treated LDL-cholesterol level.³ However, this correction factor was not employed for patients with suspected non-compliance. Similarly, where baseline LDL-cholesterol levels were unavailable, the highest untreated LDL-cholesterol level recorded prior to the study was used to calculate the DLCNC score.

Follow-up consultation and management

Management of patients continued through their GP at the research practices with consensus opinion and advice available as required.^{2, 4-6} High complexity FH, including those with symptomatic and/or advanced subclinical ASCVD, were referred to non-GP specialists with continuing GP follow-up. Patients assessed as low (i.e no other major risk factor; no symptomatic or subclinical CVD) and intermediate (i.e >1 other major CVD risk factors; early subclinical CVD) complexity FH were GP managed with additional support available from specialist as required.¹ The study included patients already diagnosed with FH in the follow-up consultation and management as part of our pragmatic primary care-based model of care for FH.

As part of usual care, patient attendances were at the discretion of patients themselves reflecting real-world, primary care clinical experience. Patients attending their GP received counselling and advice on cholesterol-lowering medication (any and/or high potency) plus lifestyle management advice including diet, exercise, body weight and smoking cessation, if

applicable. Changes in plasma lipids, proportion taking cholesterol-lowering medication and lifestyle factors were monitored during follow-up. GPs and PNs were encouraged to construct family trees to record the identity and number of close family members suitable/available for cascade testing.

Patient and public involvement

A 'community conversation' forum organised in collaboration with the WA Consumer and Community Health Research Network, the FH Support Group and FH Australasia Network was held in June 2016 prior to study commencement in WA.² The forum discussed the study protocol and sought input from participants on aspects of study delivery including involvement of close relatives at increased FH risk. A further 'community conversation' organised in collaboration with the WA Health Translation Network's (WAHTN) Consumer and Community Involvement Program held in October 2020 reflected on study progress including approaches to improve cascade testing of relatives and increase community FH awareness.

References

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2. Arnold-Reed DE, Brett T, Troeung L, *et al.* Detection and management of familial hypercholesterolaemia in primary care in Australia: protocol for a pragmatic cluster intervention study with pre-post intervention comparisons. *BMJ Open* 2017; 7:e017539.
3. Troeung L, Arnold-Reed D, Chan She Ping-Delfos W, *et al.* A new electronic screening tool for identifying risk of familial hypercholesterolaemia in general practice. *Heart* 2016;102:855-61.
4. Australian Institute of Health and Welfare. Medicare-subsidised GP, allied health and specialist health care across local areas: 2013–14 to 2018–19 <https://www.aihw.gov.au/reports/primary-health-care/medicare-subsidised-health-local-areas-2019/contents/introduction>. Access 27 Oct 2020
5. Brett T, Qureshi N, Gidding S, *et al.* Screening for familial hypercholesterolaemia in primary care: Time for general practice to play its part. *Atherosclerosis* 2018;277:399-406.
6. Brett T, Watts GF, Arnold-Reed DE, *et al.* Challenges in the care of familial hypercholesterolemia: a community care perspective. *Expert Rev Cardiovasc Ther* 2015;13:1091-100.

Supplementary Figure 1 Individual change in plasma concentration of LDL-cholesterol in patients who had one (A), two (B) and three (C) follow-up lipid profile following GP consultation.

