

Innovating for Improvement

Implementation of an Innovative e-consult Integrated Care Pathway to Improve Community-based Management of Non-Alcoholic Fatty Liver Disease in East Yorkshire

Hull and East Yorkshire Hospitals NHS Trust



About the project

Project title: Implementation of an Innovative e-consult Integrated Care Pathway to Improve Community-based Management of Non-Alcoholic Fatty Liver Disease in East Yorkshire

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Part 1: Abstract

Liver disease is the only major cause of mortality that is increasing in prevalence in the UK. Non-alcoholic fatty liver disease (NAFLD) is the most common type, affecting 25% of adults, 70% of people with diabetes and 90% of those who are morbidly obese.

Despite its prevalence, there are few defined management pathways for NAFLD patients. Most patients are diagnosed in primary care, but current community-based management is poorly defined with significant gaps in expertise.

While many patients have 'simple' NAFLD, some patients progress to more severe forms, including cirrhosis or liver cancer. Deciding when to refer patients to a liver specialist is a challenge for GPs.

This innovative project from Hull and East Yorkshire Hospitals NHS Trust brings together GPs and liver specialists through an e-consult clinic, as part of an IT-based integrated care pathway for NAFLD (NAFLD e-ICP).

The NAFLD e-ICP will standardise and improve care by detailing necessary investigations to determine the cause and severity of liver disease, and will promote early and accurate diagnosis.

Patients presenting in primary care with abnormal liver function tests will be entered onto the NAFLD e-ICP. GPs will make a referral decision: to manage them in primary care or refer them to a specialist. In complex cases, GPs will also have the option of referring the patient virtually for an e-consultation with a specialist. The specialist will review the patient data and provide appropriate management and follow-up advice.

Patients will benefit from reduced clinic appointments and duplicated investigations, earlier diagnosis and more appropriate referrals.

In an earlier pilot study we developed a paper based NAFLD Integrated Care Pathway. However, we found integrating an electronic version into SystemOne, a commonly used GP IT patient database, was more challenging than expected. We decided to look for an alternative solution and we found one in the Electronic Referral System (ERS) that GPs currently use for 'Choose and Book' appointments.

We worked closely with Clinical Commissioning Groups and the Hull and East Yorkshire Hospitals NHS Trust IT department to integrate the NAFLD e-ICP into the clinical service directory using the ERS as the mechanism for referral. Almost all of the pertinent primary care blood test results are auto-populated into the referral form. It proved to be a viable tool in its new form and GPs liked it because it was a referral mechanism they were used to using. Unfortunately the interactive NAFLD educational tool for use by GPs could not be integrated into the same package. Now, GPs access it through a separate web link. They have identified this as a barrier, largely due to time pressures and short 10 minute consultation slots. Uptake of the NAFLD educational tool has not been as high as we would have liked.

We received Health Research Authority (HRA) approval to conduct our research and GP practices were allocated to either the NAFLD e-ICP group (n=4) or to the Standard Care group (n=4). An even split of GP practices were located geographically in Hull and in East Yorkshire. The delay at the beginning of the project has clearly impacted significantly on our capacity to recruit and measure

project outcomes. We had only 6 months in which to prospectively recruit 200 participants. To date, we have recruited 22 patients with 16 consents pending. We expect to receive more referrals over the coming months. Much of the patient mapping data is not yet available as it can take several weeks for patients to finish the NAFLD disease assessments in primary care. We do however, have early patient mapping data for 18 participants. Results indicate that the NAFLD e-ICP has the potential to improve practice. Fewer of the NAFLD e-ICP patient referrals had missing liver assessment results and the time from first presentation to referral was quicker. We also have patient experience and quality of life data that indicates that the project is valued by the participants, particularly where the severity of liver damage can be quantified. These early results support the validity of the NAFLD e-ICP and the project team intend to continue recruiting participants after project funding ends on March 2017.

In July 2016, NICE published its NAFLD guidelines, which included in its recommendations the use of Enhanced Liver Fibrosis (ELF) biomarker testing in primary care to assess the severity of liver damage. This test is not yet available routinely in the NHS. The ELF test was already included in our NAFLD e-ICP for research purposes. We will use the ELF test results to measure outcomes such as appropriate GP referrals, and we will inform patients and GPs about disease severity, which will guide disease management, monitoring and referral decisions.

Even though we designed the NAFLD e-ICP model to be user-friendly for GPs, time pressure is a barrier to implementing the NAFLD e-ICP to its full potential. The GPs involved in this project have been proactive in supporting it and continue to recognise its importance in addressing an increasingly prevalent disease.

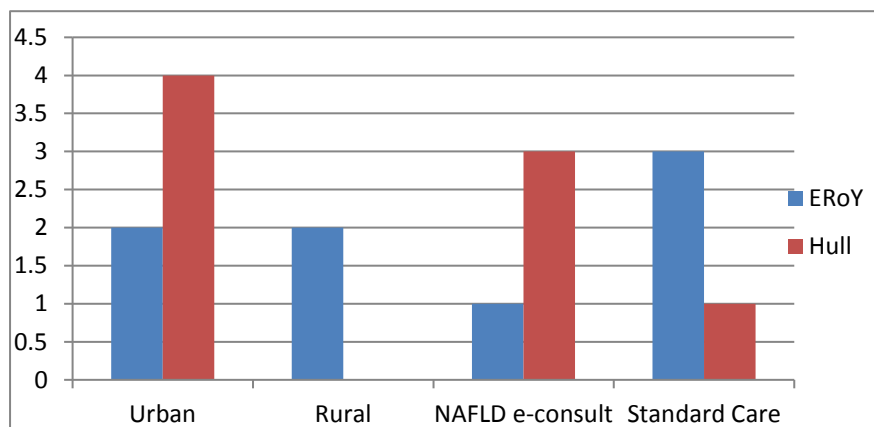
Key lessons learned include: the need for good clear communication; developing, maintaining and understanding professional relationships in specialities other than our own; and perhaps above all, to have confidence to know that if something is not working then you may need to go back to the drawing board and find alternative solutions to difficult problems.

Part 2: Progress and outcomes

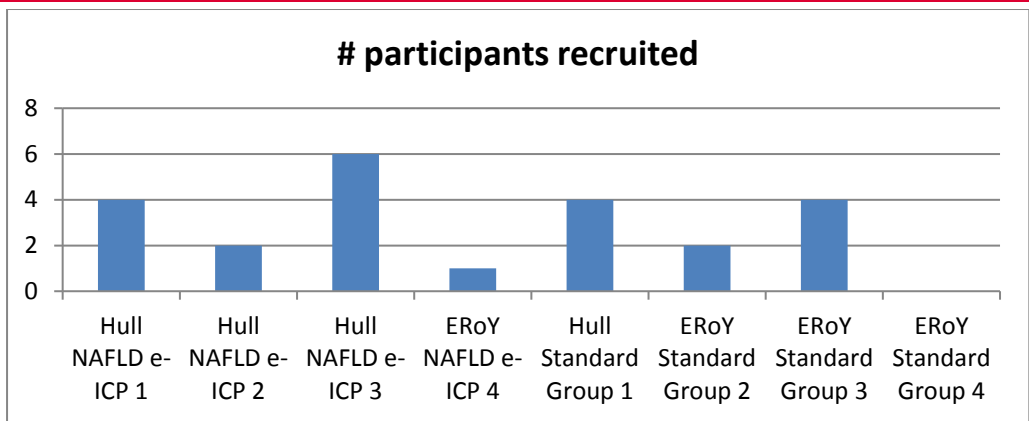
The major anticipated outcomes as outlined in our grant application were:

- 1) Increased GP confidence and expertise in NAFLD management over time, with subsequent reduction in secondary care referrals
- 2) Demonstrating superiority of the e-consult ICP over current practice will lead to adoption of this approach across the region and beyond
- 3) A swifter and more clearly defined patient journey with fewer unnecessary investigations and appointments
- 4) Clearer guidance and explanation of NAFLD and future implications from GPs to patients, strengthening the doctor : patient relationship and empowering patients to take responsibility for self-management of NAFLD
- 5) Improved access to specialist hepatology advice

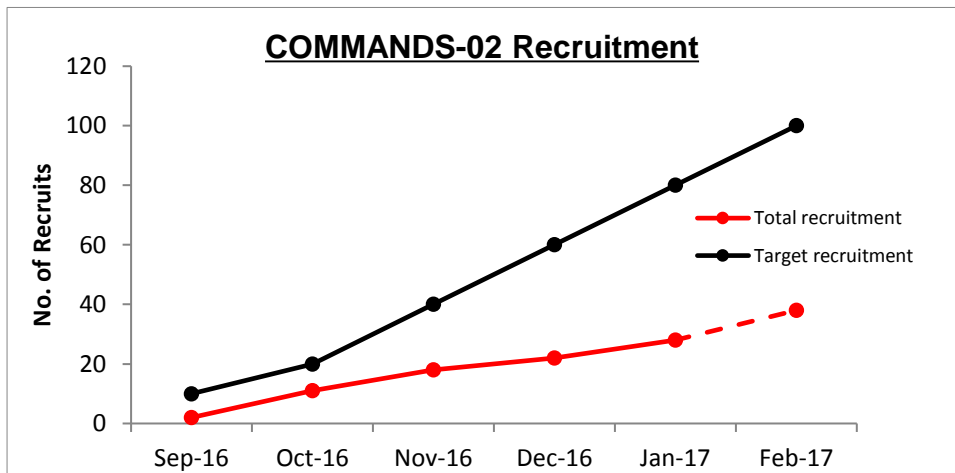
We implemented the NAFLD e-ICP project in GP practices. 4 were allocated to the NAFLD e-ICP group and 4 to standard care.



1 GP practice did not recruit any patients to date, although we do now have patients waiting to consent. Additional training and site visits are taking place to identify barriers affecting recruitment. Time was the most common reason given by GPs for not recruiting. The care pathway referral mechanism, was cited as being difficult to follow at the outset of the study. 7 GP practices have been active in identifying patients and referring them to the research team for consent.



To date, recruitment has been slower than anticipated. GPs state that patients do present with suspected NAFLD but not all have been referred to the research team. We need to explore this issue in more detail at the stakeholder feedback sessions due to be held in February 2017.

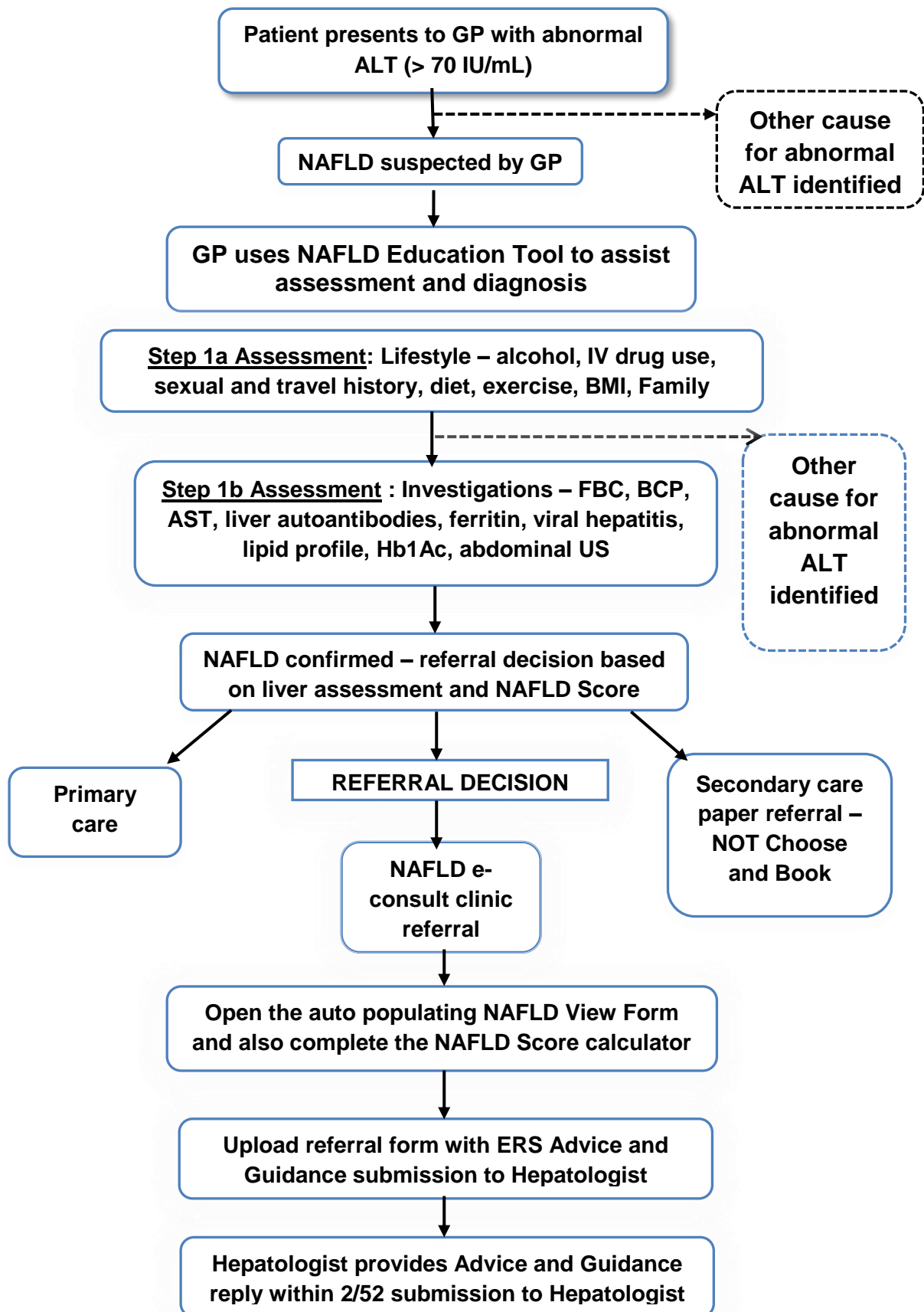


We had intended to recruit 200 patients, 100 in each group (NAFLD e-ICP and Standard Care). Due to the delay in starting recruitment we have not reached this target. We intend to continue to recruit to the end of the project period and beyond.

However, our early data does show promising results that indicate the NAFLD e-ICP model has the potential to bring about positive change. GP knowledge and practice appears to be improved from baseline and in comparison to the standard care group. Patient outcomes have yet to be fully mapped, but inappropriate referrals appear to be reduced. There are some potentially interesting trends emerging from the patient experience and quality of life data as well. Patients appear to be generally satisfied with the quality of life in terms of family, close relationships and careers, but much less so in public, social and recreational activities.

The Project developed the NAFLD e-ICP to support the achievement of these outcomes. The NAFLD e-ICP is shown below as a flow diagram.

NAFLD Advice and Guidance e-consult Referral Service via ERS



Only the GPs in the NAFLD e-ICP group were given this flow diagram, access to the e-consult referral option and access to the web based NAFLD educational tool.

The Standard group GPs were asked to continue to manage patients without changing practice.

Results for Project outcomes 1, 2 and 3

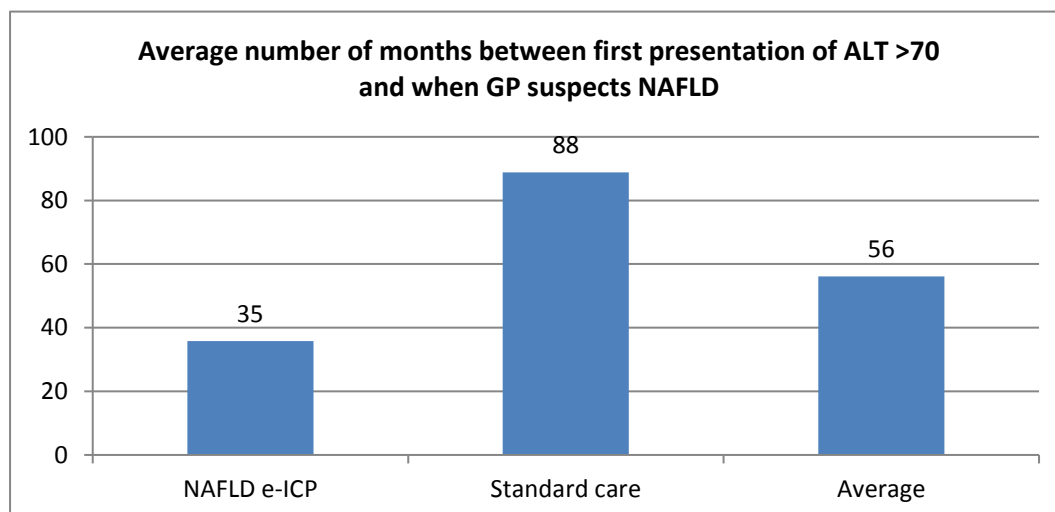
- 1) Increased GP confidence and expertise in NAFLD management over time, with subsequent reduction in secondary care referrals
- 2) Demonstrating superiority of the e-consult ICP over current practice will lead to adoption of this approach across the region and beyond
- 3) A swifter and more clearly defined patient journey with fewer unnecessary investigations and appointments

We mapped patient data as it was recorded. There were no external data recorders. Data collection parameters were clearly defined at the outset with no introduction of bias. The same data collection form was used for all patients.

We chose the 'last 10 patients recruited' methodology to map patient journeys. Unfortunately as recruitment is behind target, only the last 5 patients recruited to each group has complete early patient journey data.

Patient mapping results shown in this report are for the early stages of the patient journey only – from first presentation at the GP practice to completion of the liver assessments. As there is a time lag between first presentation and referral decision, not all patient mapping data is available. Due to the small sample size care should be taken when considering the results in this report.

Emerging trend 1: NAFLD e-ICP patients appear to have more timely care than those on Standard Care.



Emerging trend 2: NAFLD e-ICP patients appear to have more complete liver assessment data, as compared to our pilot study in 2013 and to the standard group patients. Some assessments were 'partially' completed.

COMMANDS-01 Pilot Baseline data (2013)

Routine NAFLD investigations	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Body Mass Index	Done	Done	Not Done	Not Done	Done
Weekly alcohol intake	Done	Done	Not Done	Not Done	Not Done
Risk Factors for liver disease	Not Done	Not Done	Not Done	Not Done	Not Done
Ultrasound	Done	Done	Not Done	Done	Not Done
Blood tests for disease aetiology	Not Done	Not Done	Not Done	Done	Not Done
GP diagnosis	NAFLD	NAFLD	NAFLD	NAFLD	None
Referral to hepatology	No	Yes	Yes	No	No

NAFLD e-ICP (Last 5 Patients with early patient mapping data 2016)

Routine NAFLD investigations	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Body Mass Index	Done	Done	Done	Done	Done
Weekly alcohol intake	Done	Done	Done	Done	Done
Risk Factors for liver disease	Done	Done	Partial*	Done	Not Done
Ultrasound	Done	Done	Done	Done	Done
Blood tests for disease aetiology	Done	Partial*	Not Done	Done	Done
GP diagnosis	NAFLD	Pending	Pending	Pending	Pending
Referral to hepatology	Yes	Pending	Pending	Pending	Pending

- 1 test only missing from the complete data set

Standard Care (Last 5 Patients with early patient mapping data 2016)

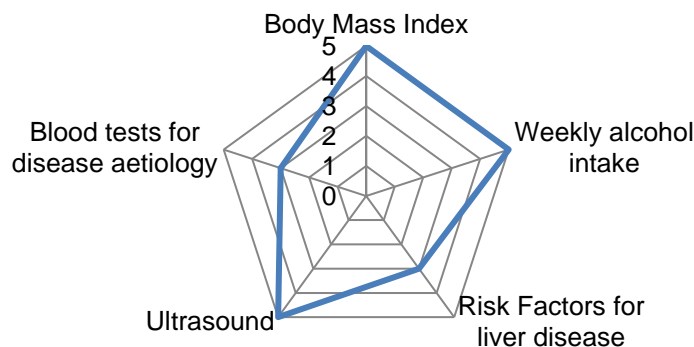
Routine NAFLD investigations	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Body Mass Index	Done	Done	Done	Done	Done
Weekly alcohol intake	Done	Done	Done	Done	Done
Risk Factors for liver disease	Not Done	Not Done	Not Done	Not Done	Not Done
Ultrasound	Done	Done	Done	Done	Done
Blood tests for disease aetiology	Not Done	Not Done	Partial*	Not Done	Not Done
GP diagnosis	Yes	No	No	No	Yes
Referral to hepatology	No	No	No	No	No

- 1 test only missing from the complete data set

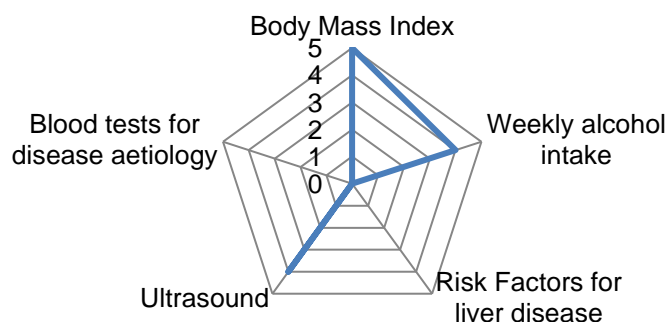
Emerging trend 3: We expected the abdominal ultrasound to be a bottle neck in completing the full liver assessment. However, 100% and 90% of patients had an ultrasound result in the NAFLD e-ICP and Standard Care groups respectively.

Emerging trend 4: The assessments most often missed are those that take place in the consultation room. This is particularly pronounced in those patients in the Standard Care group. This indicates that it is not simply lack of time that is a factor but knowledge as well.

Completion of liver assessment in the NAFLD e-ICP group in the last 5 patients recruited



Completion of liver assessment in the Standard Care group in the last 5 patients recruited



Results for Project outcome 4

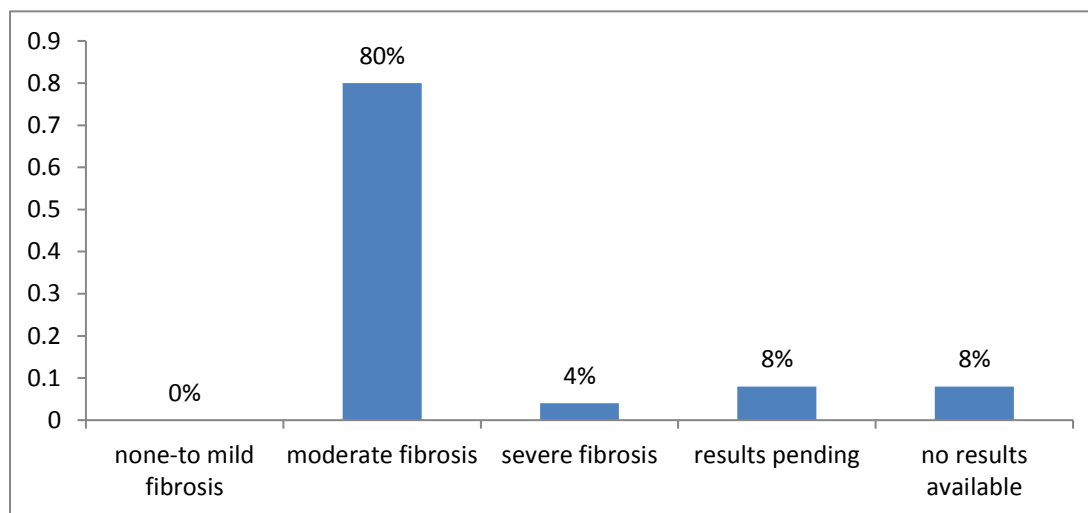
- 1) Clearer guidance and explanation of NAFLD and future implications from GPs to patients, strengthening the doctor : patient relationship and empowering patients to take responsibility for self-management of NAFLD

The recommendation of ELF biomarker blood testing in primary care in the NAFLD NICE guidelines in July 2016, has brought attention to the importance of assessing disease severity in primary care. Despite the recommendation, ELF testing is not

used in primary care. Our project included ELF testing in the NAFLD e-ICP model to stage disease severity and guide referral decision and disease management.

All patients recruited have had an ELF test. GPs and patients will receive the ELF result once a referral decision has been made to avoid influencing patient mapping data.

Emerging trend 5: Almost all patients have moderate severity disease on ELF test. 1 patient had severe disease (cirrhosis) that required immediate referral to secondary care. 21 patients had moderate severity disease which may be managed in primary care, with ongoing monitoring and positive healthy lifestyle change.



Emerging trend 6: The right patients have been identified by GPs for further investigation in primary care. No patient had a zero/mild severity result. GPs appear to suspect NAFLD in the correct group of patients.

Emerging Trend 7: Patients like the NAFLD e-ICP and ELF test option.

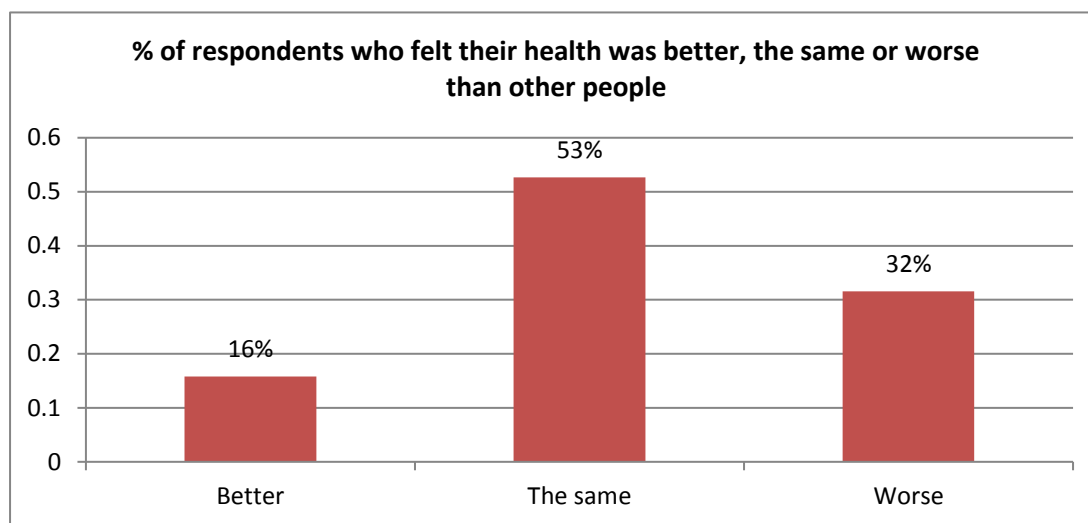
Case study 1: One patient expressed his thanks, firstly for giving him an opportunity to participate in research, but secondly that finally someone was looking more closely at managing his abnormal liver blood tests. He said that he had known they were abnormal for some years now, but that no one seemed to really know whether he should be concerned about them or not. He could not understand this. He felt that he had had unnecessary blood tests at his GP practice over the years, wasting his time and the GPs time. Once NAFLD and its symptoms were explained to him and why it is so difficult for GPs to sometimes know what to do for the best, he could understand why a better way to manage his NAFLD was needed. He was very happy to consent to the study and be part of finding a better way for his GP to manage NAFLD in primary care.

Case study 2: One patient was very anxious about her abnormal liver tests and had been told she had NAFLD. She had few of the obvious risk factors for NAFLD, was physically active and had a healthy vegetarian diet. Sometimes patients do not have the usual risk factors but can still be at risk of disease progression. Whilst not needing a referral to secondary care (as shown from the ELF test result) her GP will monitor her for signs of disease progression.

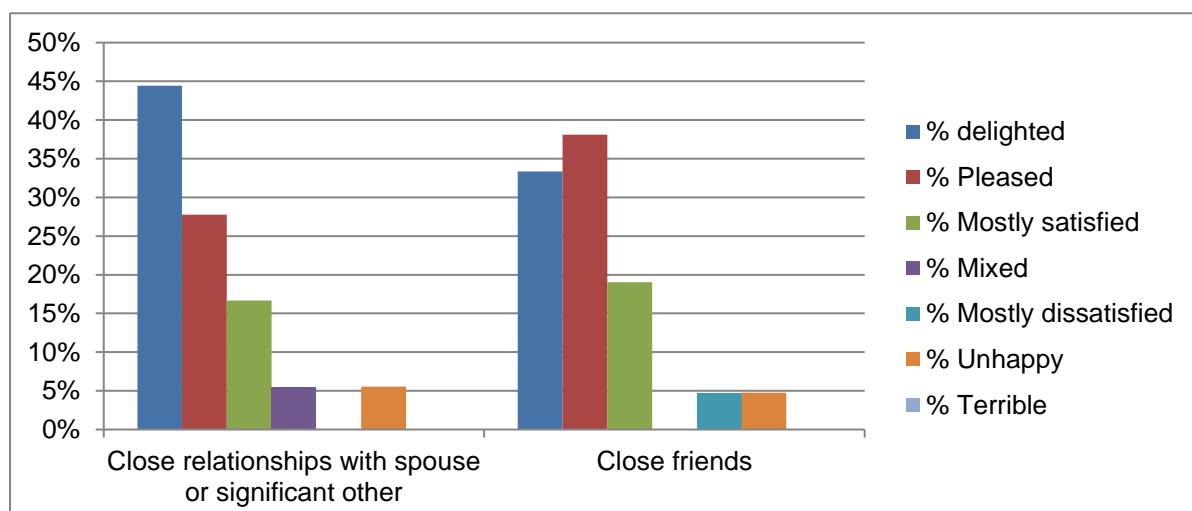
Emerging Trend 8: Quantitative evidence of disease severity can be a big motivator for patients and helps GPs tailor their advice and support accordingly.

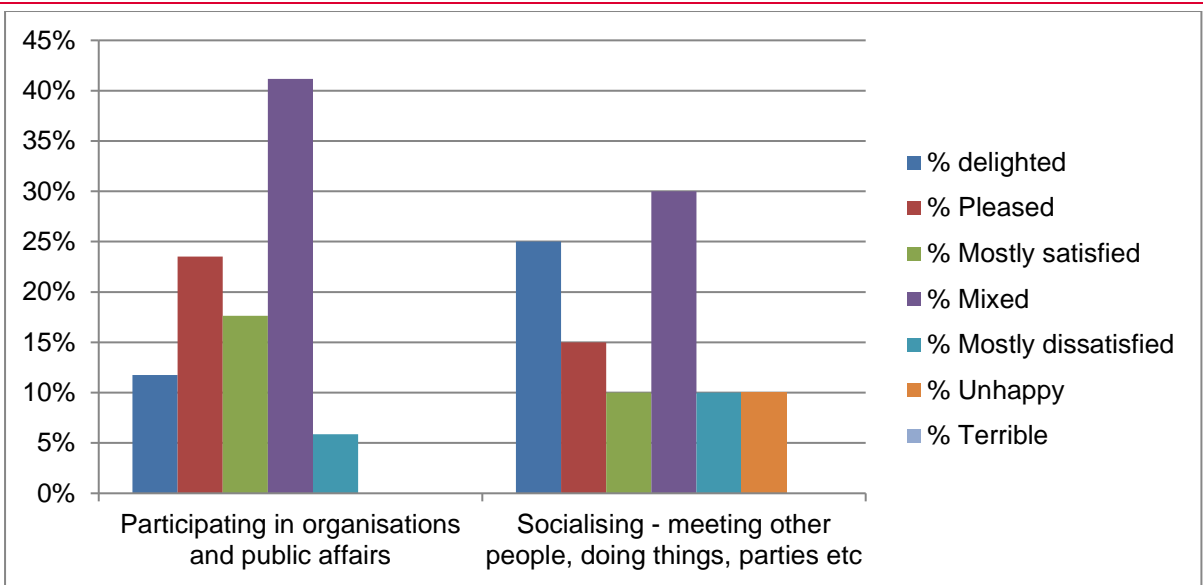
A huge benefit in having the NAFLD e-ICP and ELF test is the GPs ability to reassure patients that they are being looked after most appropriately. Disease progression to more severe disease generally occurs slowly and can be reversed by implementing healthy lifestyle changes.

Most patients who have consented to the study (90% of those approached) have had similar stories of being told they have NAFLD but not really knowing how bad it was and how worried they should be about it. The ELF test provides a more understandable indicator of what management decisions need to be made. Knowing the ELF test result may encourage patients to make important decisions about changing to healthy lifestyles.



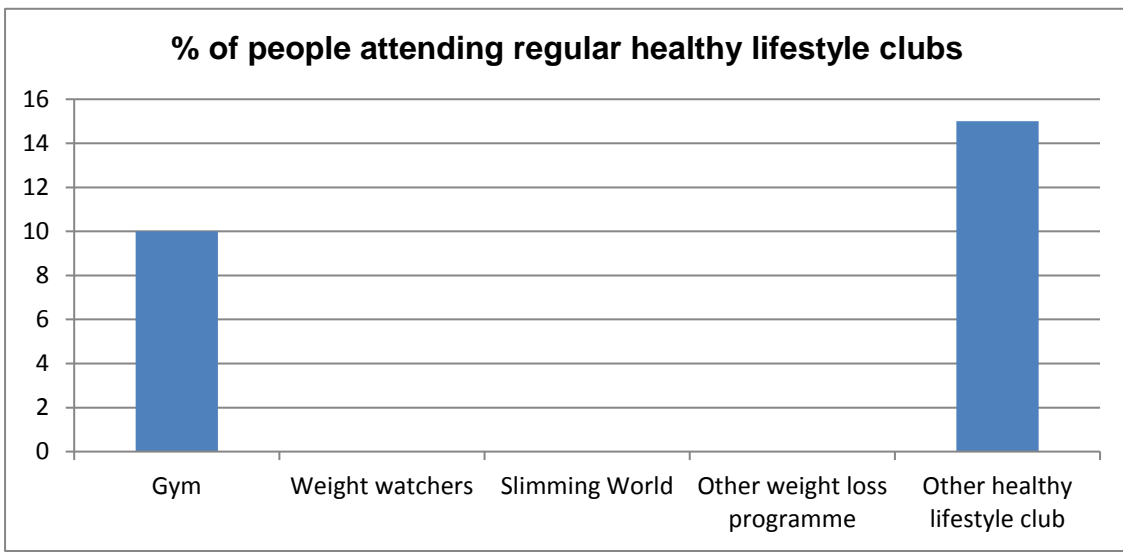
Emerging Trend 9: NAFLD patients appear to have negative feelings about their state of health. Only 16% felt their health was better than others and 32% of patient felt their health was worse than other people. Patient questionnaires reveal that many patients lack self-confidence outside their network of close family and friends.



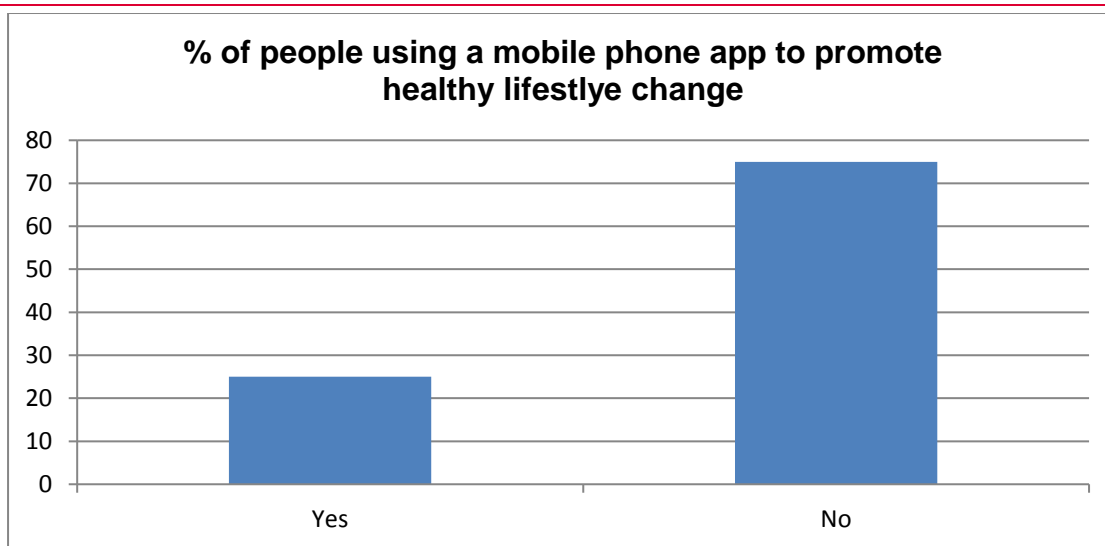


Emerging Trend 10: All patients knew that losing weight and taking up exercise are the key ways to reverse NAFLD.

Despite knowing about healthy lifestyles and how effective positive changes can be, many patients had not participated in organised healthy lifestyle changes such as diets or exercise programmes.



Many patients responded that they are not satisfied with their social lives or in participating in recreational clubs. It is surprising therefore that not more people have made use of mobile phone apps aimed at promoting healthy lifestyles.



Results for Project outcome 4

2) Improved access to specialist hepatology advice

Insufficient data is available for this outcome measure as patient referrals to the e-consult clinic are in the later stages of the patient mapping process. However, of the 6 e-consult clinic referrals made, the one and only secondary care referral made to date, was advised via the e-consult clinic. The referral mechanism appears to work well, with no communication issues arising.

5 e-consult clinic referrals had incomplete GP data and were rejected with liver specialist advice and guidance. The e-consult clinic can only be useful if the liver specialist has full access to the primary care test results. 1 patient was referred before being recruited to the study and could therefore not be accepted. The patient has since been recruited and the GP is completing liver assessment tests.

More data will be available as patient journeys are fully mapped

Part 3: Cost impact

Patient mapping is not yet at the stage where we can analyse cost savings. Caution must be taken when using these results to evaluate the project as the results are project extrapolations compared to our COMMANDS pilot study data (2012).

Emerging Trend 11: There is potential for cost savings if the ELF test is used in primary care.

Based on project results, only 1 patient out of 18 needed a secondary care referral.

Preliminary financial benefits

	Pilot study Patient numbers / clinic costs (n=20)	COMMANDS-02 NAFLD e-ICP patient numbers / clinic costs (n=18)
Primary care referral costs		
Number of patients referred to secondary care	17 (85%)	1 (5%)
GP costs (£230 / new patient referral)	£230	£230
Total costs of new patient referrals	£3910	£230
Total cost of referrals	£3910	£230
Secondary care referral costs		
Number of follow-up visits in secondary care (average 3 / patient)	51	3
Secondary care follow-up clinic costs (£108 / visit)	£5,508	£324
Total cost of referral and secondary care clinics	£9418	£554
Savings made through referrals via the NAFLD e-ICP	n/a	£8,864

Knowing that 25% of the adult population has NAFLD, 60,000 of the Hull and East Yorkshire population will have NAFLD. Not all of these people will present at the GP practice of course. But if an estimated 10% present at the GP practice each year, 6000 people will have a liver assessment.

Based on project findings where 5% of patients need a secondary care referral as shown above, we estimate there will be further savings to be made.

Primary care referral costs	Extrapolated Pilot study Patient numbers / clinic costs (n=6000)	Extrapolated NAFLD e-ICP results (n= 6000)
Number of patients referred to secondary care	5100 (85%)	300 (5%)
GP costs (£230 / new patient referral)	£230	£230
Total costs of new patient referrals	£1,173,000	£69,000
Total cost of referrals	£1,173,000	£69,000
Savings made through referrals via the NAFLD e-ICP	n/a	£1,104,000
Secondary care referral costs	Extrapolated Pilot study Patient numbers / clinic costs (n=6000)	Extrapolated NAFLD e-ICP results (n= 6000)
Number of follow-up visits in secondary care (average 3 / patient)	5100 x 3 = 15,300	300 x 3 = 900
Secondary care follow-up clinic costs (£108 / visit)	15,300 x 108 = £1,652,400	900 x 108 = £97,200
Total cost of referral and secondary care clinics	£2,825,400	£166,200
Savings made through referrals via the NAFLD e-ICP	n/a	£2,659,200

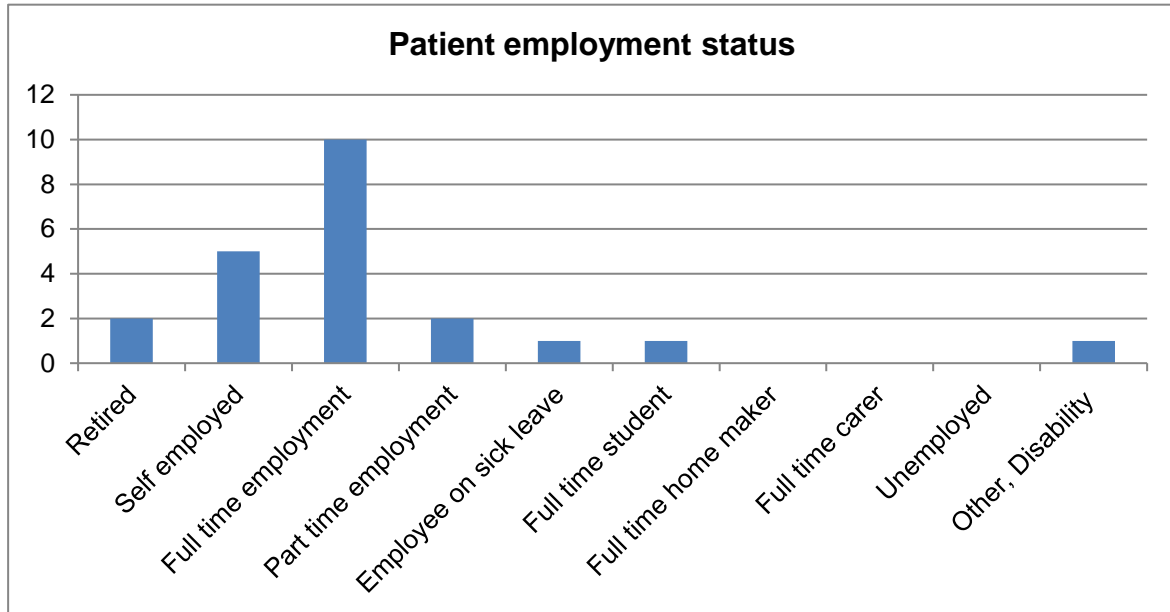
The number of inappropriate referrals in the pilot study was 41% but 0% on the current study. The ELF test is an important trigger for referral. Currently, the ELF test is only processed at the Royal Free Hospital in London. One test costs £50 plus local laboratory processing and postage, giving a total cost of £85. Cost is one of the barriers to implementing ELF tests in primary care.

However, If an estimated 6000 patients had an ELF test in primary care each year, this would cost £510,000 but would still represent a potential saving of £2,149,200.

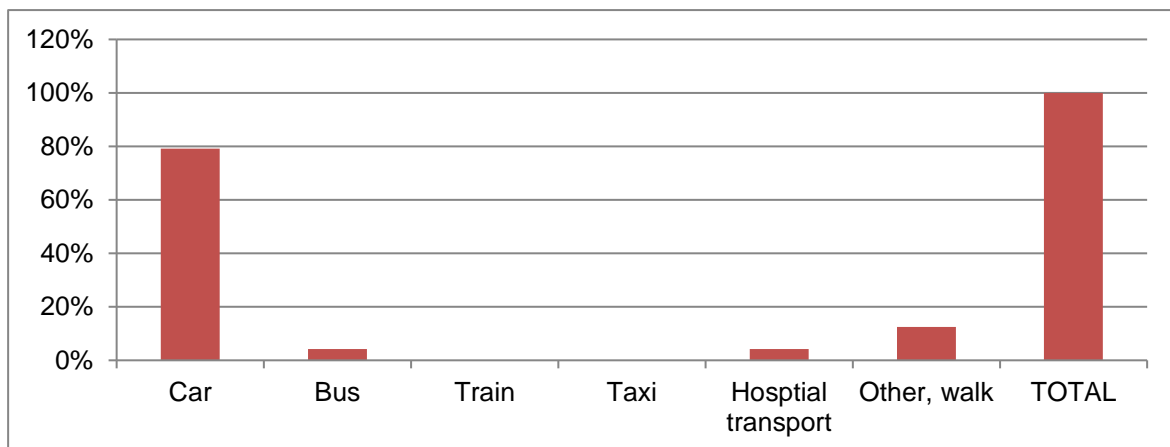
Clearly further data collection needs to be undertaken to establish true cost savings. Indeed, the feasibility of conducting ELF testing in primary care needs exploring further, particularly into the capacity of local laboratories to process and courier samples to London, or indeed to start ELF testing locally.

Emerging Trend 12: Patients will save Out of Pocket expenses.

Reduced referrals to secondary care will ensure patients will not have to spend money on car parking, taking time off work or child care. The majority of patients are self-employed or in full time employment. Quite a few of the patients recruited mentioned concerns about taking time off work, particularly when possible redundancies are looming. Some patients will travel in excess of 50 miles return trip for every hospital appointment. Combined with long clinic delays, some patients will spend up to 4 or 5 hours attending an appointment. Reducing inappropriate referrals is very important.



Patient transport to their GP or hospital appointments



Part 4: Learning from your project

This project has suffered from delays both in integrating the model into SystmOne and when getting REC approval. Had the project started to recruit patients earlier than we did, we would have had more evidence to show that the NAFLD e-ICP is an effective tool for GPs to use in primary care. As it stands, we can say that the NAFLD e-ICP is showing potential for making positive changes in the early data that we have collected. It certainly shows that it is important that we carry on recruiting patients and collecting data. The project team has done an excellent job of working through some very difficult challenges. It would have been easy to say it could not be done, but we found alternative solutions to problems that arose, getting the project to a position where recruitment of patients could begin. We believe in the model and believe it is the right way forward.

Our ambitions and objectives were realistic overall. Our lack of experience in GP IT databases, specifically SystmOne, even though we had IT experts on the team, was telling in our attempts to navigate the administrative process for model integration. We lost 8 months of project time in attempting to get NAFLD e-ICP integration approval before deciding to try something different. Ultimately the 'new' ERS integration model we are now using has its own advantages, such as access for GPs on all primary care IT data base systems not just SystmOne. We could perhaps have looked for alternative solution earlier than we did. We would have had more time to recruit patients and collect data. However, it was also important that we exhausted all possibilities for integration with SystmOne before deciding to go back to the drawing board.

Having conducted a paper-based model of the NAFLD e-ICP in 2012, and having established good working relationships with GPs, we expected this to be a positive base from which to develop the project. This proved to be true. The challenges we have faced were essentially administrative in nature rather than any fundamental problem with the NAFLD e-ICP itself or how it was to be used in primary care.

The SWOT analysis illustrates our project positive and negative experiences.

<u>STRENGTHS</u>	<u>WEAKNESSES</u>
<ul style="list-style-type: none">• Collaboration with Stakeholders:<ul style="list-style-type: none">a) GPs, Administrators, Managersb) Patientsc) Liver Specialistsd) Clinical Commissioning Groupse) Trust IT / Service Delivery Dept• NAFLD e-ICP proof of principle <i>(potential shown in early data collection)</i><ul style="list-style-type: none">a) Effective at improving GP knowledge and practiceb) Effective at reducing inappropriate referrals	<ul style="list-style-type: none">• Delays in research implementation<ul style="list-style-type: none">a) Approval process changed halfway through the REC submissionb) Lack of technical support from TPP (SystmOne) - we changed referral mechanisms halfway through the project from SystmOne to ERSc) Budget expenditure for ELF testing and GP support costs delayed due to recruitment delays. Need to find alternative sources of funding to continue patient recruitment.

<ul style="list-style-type: none"> c) Potential for large costs savings d) Robust research methodology used: Randomised cluster control trial and comparison with pilot study data. • Patient satisfaction <ul style="list-style-type: none"> a) Patients really liked the idea of having ‘disease severity’ tests (ELF) b) Patients very keen to participate in the research study c) Patients keen to understand how their disease should be managed – to quantify how serious, or not, their NAFLD was. d) For some patients, it was the first opportunity to discuss NAFLD and its implications • Team working <ul style="list-style-type: none"> a) No changes in the research team during project implementation lead to good institutional learning b) Team believes in the model and want to make it work. We found solutions to challenges that arose even if it incurred delays c) Effective and clear communication with GPs was essential. 	<ul style="list-style-type: none"> • Incomplete NAFLD e-ICP evaluation <ul style="list-style-type: none"> a) Delays in obtaining patient journey mapping data for analysis d) GP time pressures slowed patient recruitment to the research study. e) Changes in GP leads at some practices required repeat training visits and study initiation visits • NAFLD Educational tool <ul style="list-style-type: none"> a) Lack of an easy web link for GPs to access the tool (not fully integrated as planned on SystemOne) b) Poor uptake by GPs may reduce the impact of the projects educational element c) The tool has confused some GPs by adding another element into the NAFLD e-ICP referral process. Appeared to make the referral process harder to follow
<p><u>OPPORTUNITIES</u></p> <ul style="list-style-type: none"> • Sustainability <ul style="list-style-type: none"> a) Clear potential for developing the model and expanding it into a routine service delivery model b) Generating evidence for CCG to support the implementation of the NAFLD e-ICP in the future c) The study has received supporting grants from both the Hull and East Riding of Yorkshire CCGs which will be used to continue to recruit participants to the study • Further research / project development <ul style="list-style-type: none"> a) Expansion of the project into local ELF testing in primary care - feasibility and capacity assessments b) Data is generating interesting trends which we will publish and present at conferences and peer reviewed subscriptions c) Generated GP interest and patient 	<p><u>THREATS</u></p> <ul style="list-style-type: none"> • Project continuation <ul style="list-style-type: none"> a) We intend to recruit patients to this project for as long as we can fund it b) We need to secure alternative sources of funding for the continuation of the project going forward. c) Clinical Commissioning Groups decide not to support the project as a routine service delivery initiative • ELF testing is not feasible in primary care <ul style="list-style-type: none"> a) Further exploration of ELF testing in primary care shows it is not feasible b) GPs do not continue to use the NAFLD e-ICP in the long term without financial support from the research team

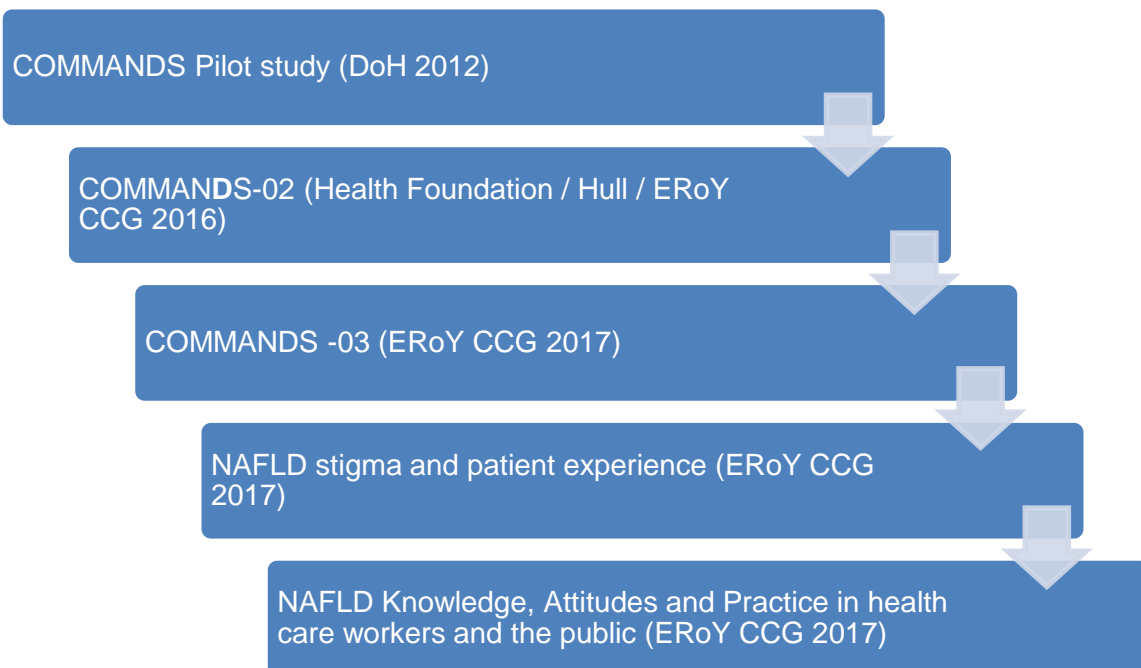
<p>interest in research and NAFLD</p> <ul style="list-style-type: none"> d) Publication of the NAFLD NICE Guidelines in July 2016 supports the project principles. e) Project has the potential to be of great interest to other areas in the UK- pending robust evidence of its effectiveness to improve patient outcomes and make cost savings. f) It is a replicable model that could be easily replicated in other areas 	
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This project has enabled the liver team at the Hull and East Yorkshire Hospitals NHS Trust to get a comprehensive understanding of NAFLD as a public health issue; as a primary and secondary care issue; of different stakeholder perspectives; and social and psychological considerations for people living with NAFLD. Altogether it has given us a holistic view of what we need to do next. It has given us the drive and direction to continue to improve care for patients with NAFLD.

Part 5: Sustainability and spread

We first conducted a paper-based NAFLD Integrated Care Pathway project in 2012. This proved popular with GPs and patients and we developed the COMMANDS-02 project, which the Health Foundation has funded. East Riding of Yorkshire and Hull CCGs have both provided small additional funding support for the project in order for us to take recruitment on beyond the Health Foundation funding period. From the current project, we have designed and applied for funding from East Riding CCG for COMMANDS-03, an ELF test feasibility and capacity assessment study. They have just this month granted approval for funding for this project. We will start the process of getting REC approval immediately.

We have also designed 2 qualitative sub-studies as part of the COMMANDS-03 application request. Firstly, a study looking at stigma and patient experience of living with NAFLD; and secondly, a study looking at Health Care Professionals, patients, carers and the public knowledge, attitudes and practice of NAFLD.



As a liver research team we are keen to look at all aspects of NAFLD in order to develop a holistic approach to care and patient experience. This will make the current COMMANDS-02 project intervention all the more sustainable going forward.

The NAFLD e-ICP model is a model that works well in primary care once GPs know how to use it and understand that it only works if all the liver assessments are completed. GP feedback in the stakeholder session being held in February 2017 will give us more detail on how well it works in real practice and whether there are any amendments needed to improve it. We do know that GP time is one of the main

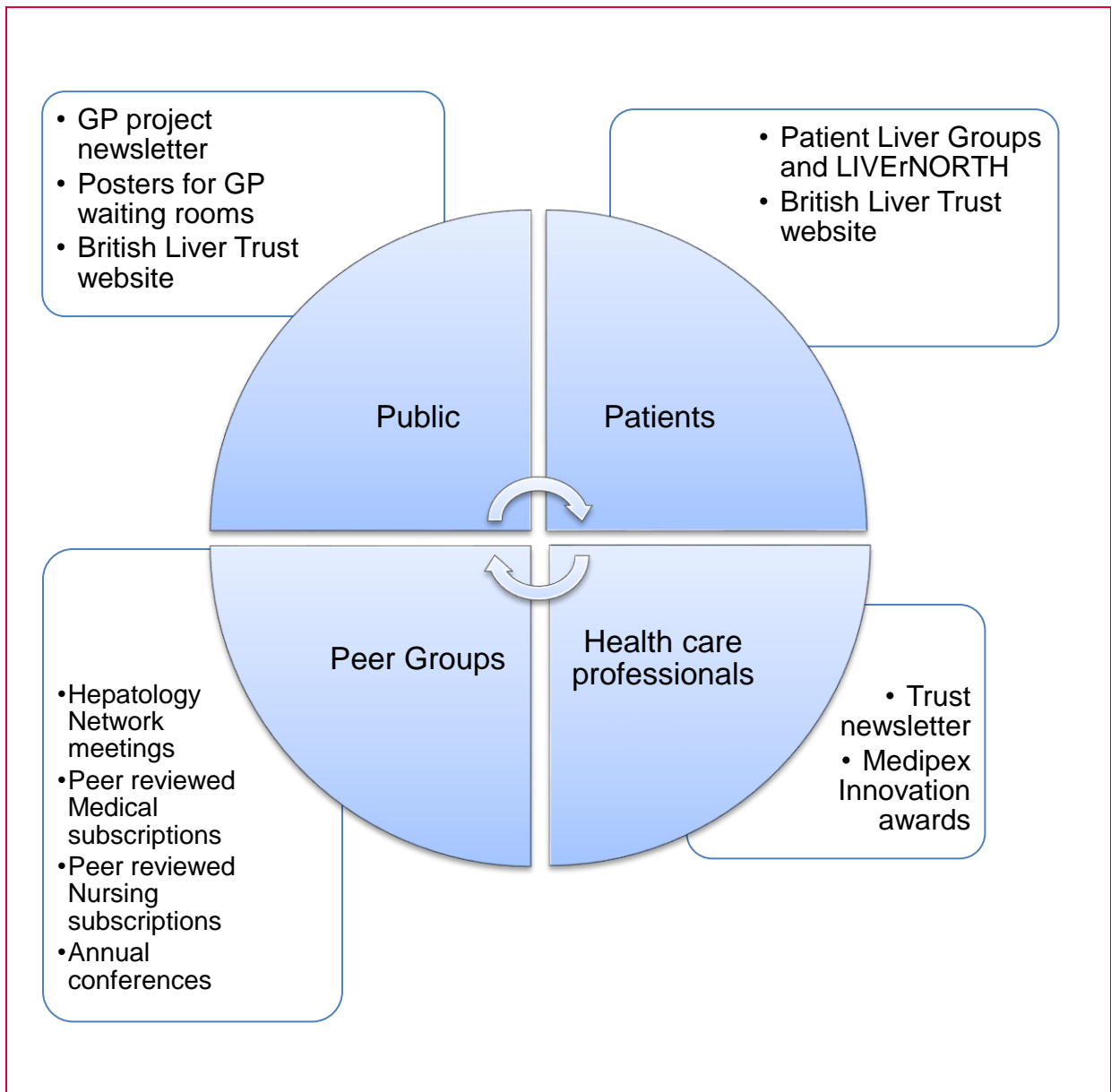
barriers to making the NAFLD e-ICP sustainable. But if we can provide enough positive evidence, both in patient outcomes and in economic savings, then the model, we believe, will be sustainable. Whether all GPs choose to take up the model once we expand its implementation beyond the current participating sites, remains to be seen. We will promote it at that point with the local CCGs, with Hepatology networks across the country and in peer reviewed subscriptions. We also have Trust sponsored Innovation Award Events where new initiatives can be presented to health care professionals. The COMMANDS pilot study won a Medipex Award for Innovation back on 2012.

We are in touch the LIVErNORTH patient group in Newcastle who reviewed our research documents for REC. They have the potential to play a big part in encouraging local CCGs and GPs to get in touch about implementing the model in their area. As the NAFLD e-ICP is now integrated into the ERS 'Choose and Book' system rather than SystmOne, it opens the model up to any GP in the NHS with access to any primary care IT database network. It is therefore not restricted to the local area, but can be replicated and expanded across the UK.

As the burden of NAFLD increases, the need for the NAFLD e-ICP model will grow. Although the ELF test is not yet available in primary care and is logistically challenging to organise on an operational level even for research teams, it is likely that this will change in the coming years, particularly as it has been recommended in the NAFLD NICE guidelines.

We have had several enquiries from research teams in the UK about participating in the project, from Nottingham to Darlington. We have also had emails from the Canadian Hepatology Nurse Association who heard about the project through the Health Foundation website. We have added these contacts to a COMMANDS-02 partner database and will contact them when we are ready to disseminate the model and its results to a wider audience.

We published one article on the Trust Newsletter about the project, one for the local Hepatology network newsletter and one for the Research Network. I will be presenting the project at the British Liver Nurse Forum annual conference in June 2017. Once we have more robust evidence from our data collection, we will be submitting abstracts and posters to the annual British Society of Gastroenterology and the European Liver Association conferences in 2017. We will also be submitting an article to Frontline Gastroenterology, Nursing Times and Gastrointestinal Nursing subscriptions in 2017.



Appendix 1

GP e-consult ICP Advice and guidance page on the Pathway Information Portal. It includes links to the NAFLD Score calculator and the NALFD education tool

Pathway Information Portal

Non-alcoholic Fatty Liver Disease

Definition

Until recently Non-Alcoholic Fatty Liver Disease (NAFLD) was considered to be rare and relatively harmless. It was not thought to progress to chronic (long-term) or serious liver disease. For most people, a fatty liver can remain free of inflammation and they will experience few symptoms.

However, for an increasing number of people, the effects of having fat in their liver, over a long period, may lead to inflammation causing scarring (fibrosis). In some people this can progress to a potentially life-threatening condition known as cirrhosis.

Today, NAFLD is recognised as one of the most common forms of liver disease worldwide and one that can progress to advanced liver damage.

NAFLD Advice and Guidance e-consult referral is for use by GPs where the need for patient referral to secondary care is unclear.

Guidelines on Management

NAFLD is a liver disease closely associated with Metabolic Syndrome (obesity, hypertension, hyperlipidaemia, type 2 diabetes). It should be managed in primary care where ever possible, by encouraging patients to make sustainable healthy lifestyle changes. However, some patients may progress to Non-Alcoholic SteatoHepatitis (NASH), cirrhosis and liver cancer. These patients will require a secondary care referral. Unfortunately, there is no way to tell who will progress to more severe forms of liver disease and it can be difficult for GPs to determine the right time for referral. In such cases, the GP may choose to refer patients to the NAFLD Advice and Guidance e-consult referral service via the e-Referral Service (eRS).

Primary Care Management should include:

- [Heathy lifestyle advice](#) (diet / exercise, smoking cessation)
- Monitor ALT / AST ratio
- Monitor NAFLD score
- Consider a secondary care referral if NAFLD score = > 0.675
- Consider a NAFLD Advice and Guidance e-consult referral if NAFLD score is between = <-1.455 and 0.676

Red Flag Symptoms

NAFLD progresses to Non-alcohol related steatohepatitis (NASH) and cirrhosis slowly or not at all in most patients. Any progressive liver disease or symptoms that

suggest acute liver disease should be referred directly to acute care.

Do Not Refer

If your patient:

- Does not have a complete set of screening results as shown on the [NAFLD care pathway](#) document
- Has any other liver disease diagnosed, other than NAFLD
- Has a higher than recommended alcohol intake
- Has a NAFLD score of > 0.676, indicating a high probability of fibrosis. Do not e-refer but refer directly into secondary care.
-

Referral Criteria

The NAFLD e-clinic referral service is currently being piloted and will be open to all GPs after its performance has been evaluated.

The patients that can and should be referred are those with a probable diagnosis of NAFLD and have identifiable potential risk factors for developing NASH, but where the need for referral is unclear. Consider the following as potential risk factors for developing NASH, cirrhosis and HCC.

- BMI > 28
- At least 2 ALT results x2 ULN over a 3 -6 month period
- Type 2 diabetes
- Alcohol intake within safe levels
- Fatty Liver noted on [ultrasound](#)
- NAFLD score = -1.455 to 0.676

A patient does not need to fulfil all of these criteria to request an Advice and Guidance e-consult referral.

This is an adult only NAFLD e-clinic referral service.

The GP practice should make a secondary care referral via ERS / choose and book if the need for a referral is clear. If the case for a secondary care management is not clear, make a NAFLD Advice and Guidance e-clinic referral. A GP should complete the NAFLD e-ICP pathway prior to making a NAFLD e-consult referral.

This NAFLD Advice and Guidance e-referral will be reviewed by a liver specialist within 1 week and you will receive a response within 2 weeks.

Referral

A referral can only be made vis ERS.

1. On the Directory of Services within E-Referral, choose the speciality GI and Liver (medicine and surgery)
2. Under clinic type select **Hepatology**
3. In the 'service results' choose Non-Alcoholic Fatty Liver Disease, Hull and East Yorkshire Hospitals (Hull Royal Infirmary) - the clinic indicates that this is for advice and guidance to GP's where the need for secondary care referral is

unclear.

Information To Include

The NAFLD score, using the [NAFLD Score Calculator](#) or the [NAFLD Educational Tool](#), should be calculated prior to referral.

When submitting the ERS Advice and Guidance referral to the Hepatologist, you will need to:

- attach the SystmOne NAFLD Referral Form (auto populated)
- input the patients NAFLD Score on the ERS Advice and Guidance e-form.

References

Reference material can be found via the Yorkshire and The Humber Liver network:

<http://www.yhln.org.uk/patient-information/non-alcohol-fatty-liver-disease-nafld/primary-care>

<http://www.yhln.org.uk/patient-information/nutrition-in-liver-disease>

Additional Information :

The NAFLD e-clinic referral service is currently being piloted and will be open to all GPs after its performance has been evaluated. See the Directory of Services on ERS (**Information in Referral above**)

[Nutrition guidance NAFLD and weight reduction](#)

[Nutrition guidance The Eatwell plate](#)

[NAFLD Calculator](#)

[NAFLD Education Tool](#)

[NAFLD Advice and Guidance Pathway](#)

Appendix 2

The interactive NAFLD Education tool (a step by step illustration of the assessment process that GPs can use).

Page 1:

The screenshot shows a web browser window displaying the 'NAFLD Care Pathway' e-ICP Educational Tool. The browser's address bar shows 'http://lcp-systemoneuk/'. The page title is 'NAFLD Care Pathway' and the subtitle is 'e-ICP Educational Tool'. A navigation bar at the top contains 'Home', 'Risk Factors', 'Severity', and 'Evidence', with 'Liver Screen' currently selected and highlighted in green. Below the navigation bar, the page content is titled 'Step 1A - Liver Screen'. On the right side of this section, there are two buttons: 'Guidance Notes' (orange) and 'Restart NAFLD Pathway' (blue). The main content area features three dropdown menus for 'Autoantibodies', 'Virology', and 'Ferritin', each with the text 'Select from list below:-'. Below these menus is a light blue box containing the text: 'Guidance for GP: Please make a selection for Autoantibodies.' The browser's taskbar at the bottom shows various application icons and the system clock indicating 09:38 on 20/10/2016.

Page 2:

NAFLD Care Pathway e-ICP Educational Tool

Home

You are here: Home

Liver Screen

Step 1A - Liver Screen

Autoantibodies Select from list below:-

Virology Select from list below:-

Ferritin Select from list below:-

Guidance for GP:

Please make a selection for Autoantibodies.

The following lifestyle risks and lab investigations should be addressed:

Lifestyle	Investigations
alcohol (previous and current)	FBC and BCP
IV drug use (previous and current)	AST
sexual and travel history	liver autoantibodies
diet and exercise (with BMI)	viral hepatitis
Family history liver disease	lipid profile
tattoos	abdominal USS
	fasting glucose
	ferritin

Guidance Notes Restart NAFLD Pathway

09:39 20/10/2016

Page 3:

NAFLD fibrosis score Online calculator

Angulo P, Hui JM, Marchesini G et al. **The NAFLD fibrosis score**
A noninvasive system that identifies liver fibrosis in patients with NAFLD
Hepatology 2007;45(4):846-854 [doi:10.1002/hep.21496](https://doi.org/10.1002/hep.21496)

Age (years)

BMI (kg/m²)

IGF/diabetes

AST

ALT

Platelets (x10⁹/l)

Albumin (g/l)

BMI: body mass index
IGF: impaired fasting glucose

Page 4: