



**Enabling Learning NHS Care Systems utilizing
Electronic Medical Records (ELeCtra) in Fife:
Innovative opportunities to support the NHS Fife
Clinical Strategy**

End of Project Report: June 2020



1. PROPOSAL

1.1 Introduction

ELeCtra has developed the Information Technology and Management Infrastructure to enable a Learning Health System (LHS) in NHS Fife. It builds upon existing local and national investments in information technology and digital health that are essential for the delivery of the NHS Scotland Clinical Strategy five-year plan. In 2008, NHS Fife made the bold decision to invest in identifying datasets with the Scottish Community Health Index Number (CHI) core and secondary NHS Fife clinical datasets. The datasets have been linked to create a cleaned, 'live' and comprehensive information system that is well governed. The main datasets used are from Information Services Division (ISD) and other national datasets, such as of the Scottish Health Research Registry (SHARE), which is a list of people in Scotland, including 28,479 in Fife, who have agreed to allow their records to be accessed for research and primary care data. This has the potential of informing, supporting and evaluating the activities undertaken as a result of the NHS Fife Clinical Strategy upon Fife citizens who are active users of NHS Scotland and associated Health and Social Care Partnerships. The exemplar studied was multimorbidity.

1.2 Aims

The aims of this project were to; -

1. Integrate existing NHS Fife datasets hosted by HIC, EMIS Web and SHARE to a virtual comprehensive electronic health record for use in pilot and feasibility studies funded by the NHS Fife Endowment Fund Grants Programme.
2. Provide an enhanced platform to access this data for NHS Fife staff at Royal Victoria Hospital, Queen Margaret Hospital and the University of St Andrews (USTAN) building on HIC's existing Safe Haven infrastructure (Appendix).
3. Develop knowledge transfer methods to ensure that research evidence influences policy and clinical practice.

1.3 Project Timeline

This initial project proposal was for one year but was extended due to delays and the Covid Pandemic.

1.3 Resources

Project Costs	
1) Database programmer (0.75 FTE)	£45,338
2) Programme Manager (1 FTE)	£42,587
3) Programmer (0.25 FTE)	£15,113
4) Research Assistant (0.5 FTE)	£21,294
5) Infrastructure support staff (0.25 FTE)	£15,113
6) Data Governance (0.125 FTE)	£5,941
7) Computer equipment, licences, servers, device parts	£10,000
8) Training and Dissemination Costs	£9,000
9) Statistician (0.15 FTE)	£8,750
10) Travel to meetings in Fife, Edinburgh and Dundee	£1,500
TOTAL	£174,636

1.5 Proposed project outcomes

The LHS Programme will be evaluated by providing user metrics and qualitative data on user satisfaction, in addition to evaluative work with NHS Fife researchers to identify strengths and weaknesses in the infrastructure developed.

2. INFRASTRUCTURE DEVELOPMENT

2.1 Proposed plan

In order to support the diffusion of novel clinical resources from academic studies to patients, significant Information and Communications Technology (ICT) and organizational challenges need to be overcome in the areas of interoperability, common standards for data integration, data presentation, recording, scalability, and security. This project planned to build upon earlier NHS Fife investments in ICT in the clinical and management domains, as well as investments in the Health Informatics Centre (HIC) and SHARE to drive, evaluate and validate innovations which address the priorities in the Fife Health & Social Care partnership strategic plan and Clinical Strategy. The project planned to work with data controllers for each of the sources of data, including EMIS Web for primary care data, to establish linkages between the data required, identify potential study subjects and to follow them up in the longer term.

Medical data for patients is currently distributed across a number of different systems. This creates a significant challenge for clinicians and researchers who need access to complete medical records for clinical decision making, or for addressing approved research questions. To overcome this barrier, this project planned to use the HIC Research Data Management Platform and build a virtual comprehensive electronic health record (cEHR) using local and national health data sources, which

could then be linked to project specific data held in the HIC 'Safe Haven'. The creation of a single cEHR for each patient means that servicing multiple projects from a single data source becomes very efficient. The use of this linked dataset will be strictly managed in terms of both clinical and information governance standards led by NHS Fife & the GPs, leveraging existing systems within the 'Safe Haven'. Only the data required for each specific project would be provided from the cEHR.

2.1 Development of the infrastructure

During the course of this project multiple challenges and new insights emerged impacting on the original plans stated above for the development of a single linked, comprehensive dataset. The decisions made on the development of the ELeCtra infrastructure are detailed in the sections below.

2.1.1 Step 1: Data from primary care system

Systems and software decisions

The original plan for obtaining primary care data from participating GP practices across NHS Fife incorporated the extraction of the data directly from primary care electronic health records (EHR) utilising the digital clinical system, EMIS Web. This extracted data would then be transferred to the HIC Research Data Management platform where a cEHR/linked dataset would be built consisting of linked primary care data, other local and national health data, including project specific data held within the HIC 'Safe Haven'.

It was established by October 2018 that the EMIS Web software version utilised in the NHS Fife GP practices did not support the functionality for extracting the existing clinical data to the HIC platform as required. To overcome this challenge, a software package would need to be developed for EMIS however due to the time constraints of the project, and the incorporation of commercial developers and intellectual property considerations, new collaborative connections were made in October/November 2018. The alternative software support system, EScro, an integrated reporting solution, provided by Albasoft, is already embedded in primary care within NHS Scotland and was established as a means of data extraction from the clinical database held within practices without the interruption, replacement, and/or insertion of any software system to practices engaging with the project.

In the last few months of 2018 it was established that Albasoft could provide one of two service models;

1) an automated system where data from GP practices is replicated from existing EScro database to a

central NHS server regularly at pre-defined periods i.e. weekly, monthly, 2) a managed service where Albasoft would act as a data processor extracting data from the practices to their own secure servers (Figure 1).

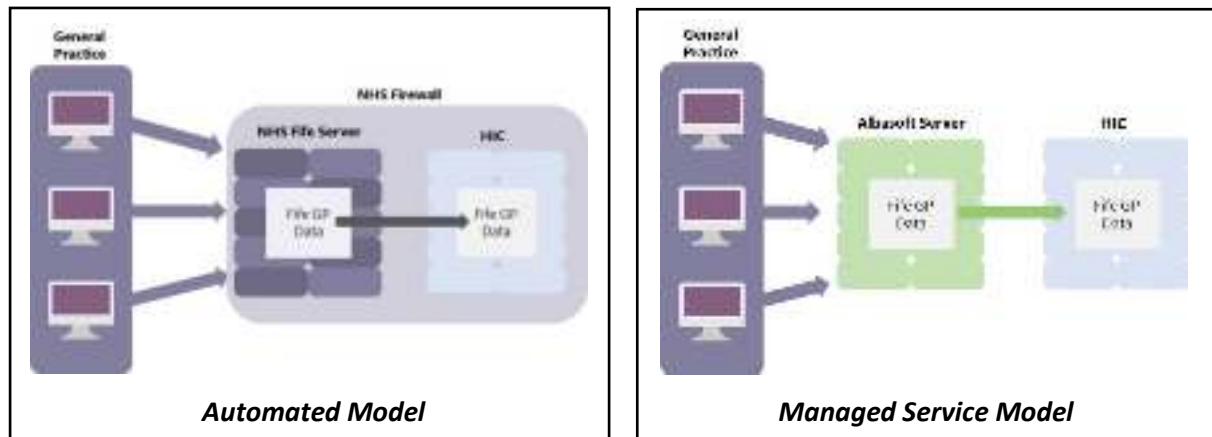


Figure 1: Data flow models from primary care GP practices

Costings & scalability considerations of data extraction model

Costing for these two models differed based on initial set-up and building of the system. The managed service model would provide significant savings on capital expenditure from NHS Fife and reduced costs of approximately up to 30% for Albasoft’s services due to the use of existing systems. However, this existing system and model would be based on a small number of practices engaged with the project thus would in the short-term, only be suitable for small piloting of the data replication. Further costs would be incurred for Albasoft’s services and NHS Fife to permit the scaling up of this model for roll-out across numerous practice engagement and long-term infrastructure development.

The automated model although more expensive upfront and requiring NHS Fife to commit to hardware related costing (NHS central server and licences for the purpose of holding the replicated and extracted data from primary care), would permit any number of practices to engage with the data sharing process. The automated model is designed to allow any number of individual practices’ databases to be enabled/disabled into the model system (following instruction from data controllers) to replicate and extract their data – ensuring the long-term scalability of the ICT infrastructure.

2.1.2. Step 2: Data flow and processing

With revisions to the process of replicating and extracting the data from primary care, continual liaison and discussion with the different members of the collaborative project team was required to ensure clarity and a consensus on the infrastructure development (Figure 2).

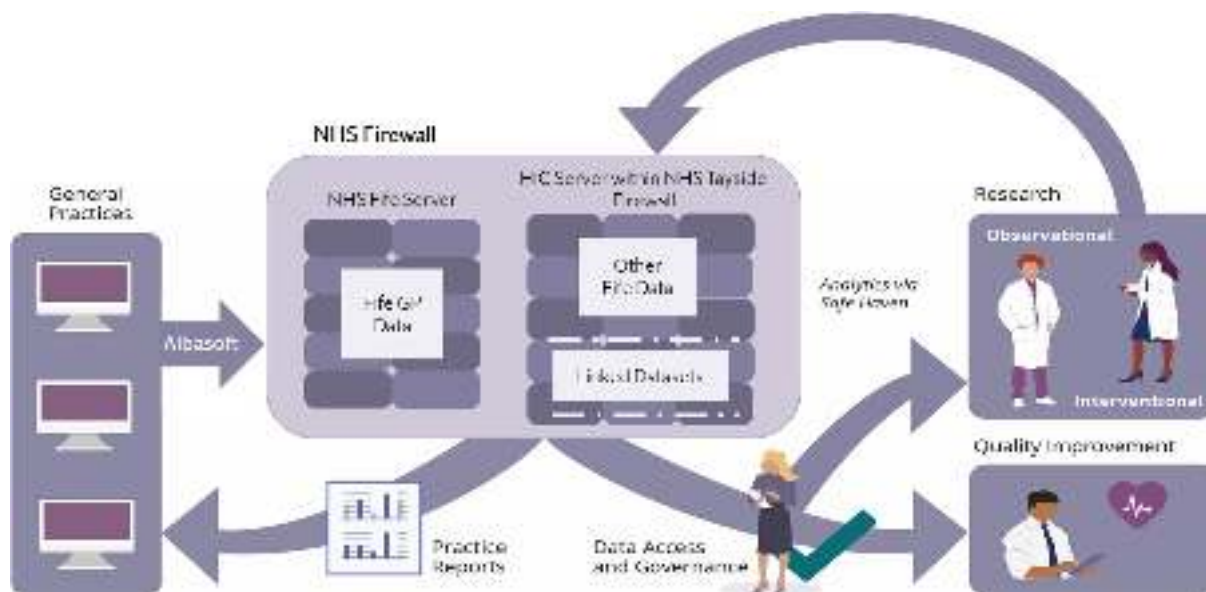


Figure 2: ELeCtra infrastructure

By the beginning of 2019, the requirements for the automated model of data replication and extraction was set. In spring of 2019, NHS Fife Information Services began the process of enquiring on the costing and purchase of a server and licences for hosting of the primary care data replicated and extracted from the GP practices.

Procurement of the NHS server and licences were obtained in January 2020 and work began in the following months between NHS Fife Information Services and Albasoft to set-up the server. Due to the unforeseen impact of the COVID-19 pandemic on the workload of both Albasoft and NHS Fife Information Services this collaborative work data replication and extraction to the NHS server was delayed until June 2020.

Throughout the discussions on the appropriate data extraction models and the set-up of the data sharing from Primary Care to the newly acquired NHS server, the team liaised with HIC team members to establish the process of sharing and moving the extracted data from the NHS server to the HIC Safe Haven platform. Central to these discussions was the need for full compliance with strict Governance considerations.

2.1.3. Information Governance and Security

During the initial few months of this project and following the newly revised GDPR guidelines in May 2018, finding out the information on how the clinical data can be shared and who controls the data at different stages of the infrastructure was a challenge. Collaboration with NHS Fife Information Governance and Security team was established in November 2018.

The automated model decided upon by the project team importantly is based on the fact that the primary care GP practices data being replicated and extracted by Albasoft is transferred to a NHS Fife server, thus the data remains within the NHS and under its governance and security and does not leave to any external server held by Albasoft or any external organisation. Ensuring that the data remains within the control of the NHS was vital in the development of this ICT infrastructure.

By spring 2019, it was established that numerous different data protection and governance agreements would be required for the development of the infrastructure and the different data flow stages (data replication & extraction; data sharing and processing; data access). The following is a timeline for the different governance agreements: -

Step 1: Data replication & extraction

- Data Protection Impact Assessment (DPIA) - May 2019
- Caldicott Approvals by NHS Fife and GPs

Step 2: Data flow and processing

- Data sharing agreement between NHS Fife and Albasoft – February 2020¹
- Data sharing agreement between NHS Fife and HIC – January 2020¹

Step 3: Data access

Throughout the development of the infrastructure the governance procedure for data access was discussed by the collaborative team. Data access considerations were needed for a) the GP practices, b) the health board, and c) researchers. The following was established; -

- For individual GP practices: no governance for data access was required for their own practice data
- For the health board: application for de-identified comprehensive linked dataset via ELeCtra Oversight Group (details of development of this committee/group in section 2.1.4)

¹ These data agreements were in place at these times indicated, however due to the COVID-19 pandemic signed hardcopies of these date agreements were not available until April 2020

- For research projects: application for de-identified comprehensive linked dataset via ELeCtra Oversight Group and then application to HIC utilising existing HIC data request process (including data user declarations)

2.1.4. Step 3: Data access

Governance and controlled access of the linked dataset was an important aspect established in the development of the LHS infrastructure. Throughout the project it was established that an ELeCtra committee/group centrally controlled within NHS Fife would need to be formed to review applications for access to the linked datasets. With vital information and support from NHS Fife Research and Development office and the wider collaborative team, the design of an ELeCtra Oversight Group (EOG) was deemed necessary. This oversight group would oversee and review requests by researchers and the health board for access to the linked datasets (Figure 3).

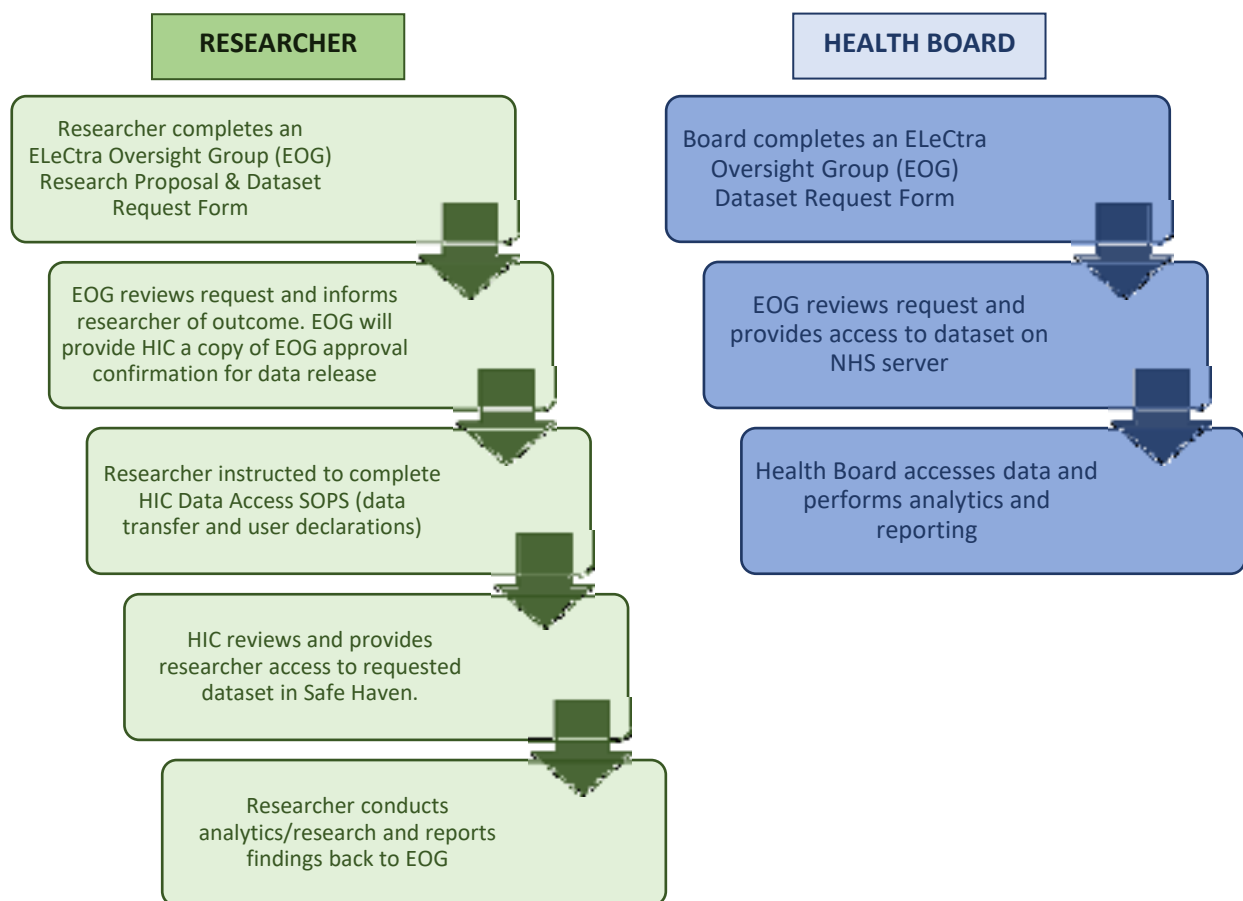


Figure 3: ELeCtra Oversight Group process of data request and access

3. PROJECT OUTCOME(S)

The main aim of this project was to integrate existing NHS Fife datasets hosted by HIC, Primary Care and SHARE into a virtual comprehensive electronic health record and provide an enhanced platform to access this data. The project has achieved the development of a working infrastructure where existing NHS Fife data from a sample of GP practices has been successfully replicated, extracted and combined with other health data held by HIC to provide a comprehensive linked dataset for NHS Fife.

3.1 EXEMPLAR REPORT ON MULTIMORBIDITY IN FIFE

Patient Population & Data Sources

HDR UK multimorbidity platform work had defined a population cohort as all patients aged 25+ on 1st Jan 2000. The data presented is all those still alive and still registered with NHS Fife on 31st December 2018.

Data was available from hospital inpatient records (SMR01 and SMR04), hospital outpatient attendances (SMR00), cancer registry (SMR06) and attendances at A&E. Other data was also available including Prescribing Information Services data but this was not used within this analysis.

The presence of the 31 different conditions represented within the Elixhauser Index based on ICD10 codes from these data sources was calculated for each individual and they were described as having multimorbidity if two or more of these conditions were present and having complex multimorbidity if 4 or more of these conditions were present.

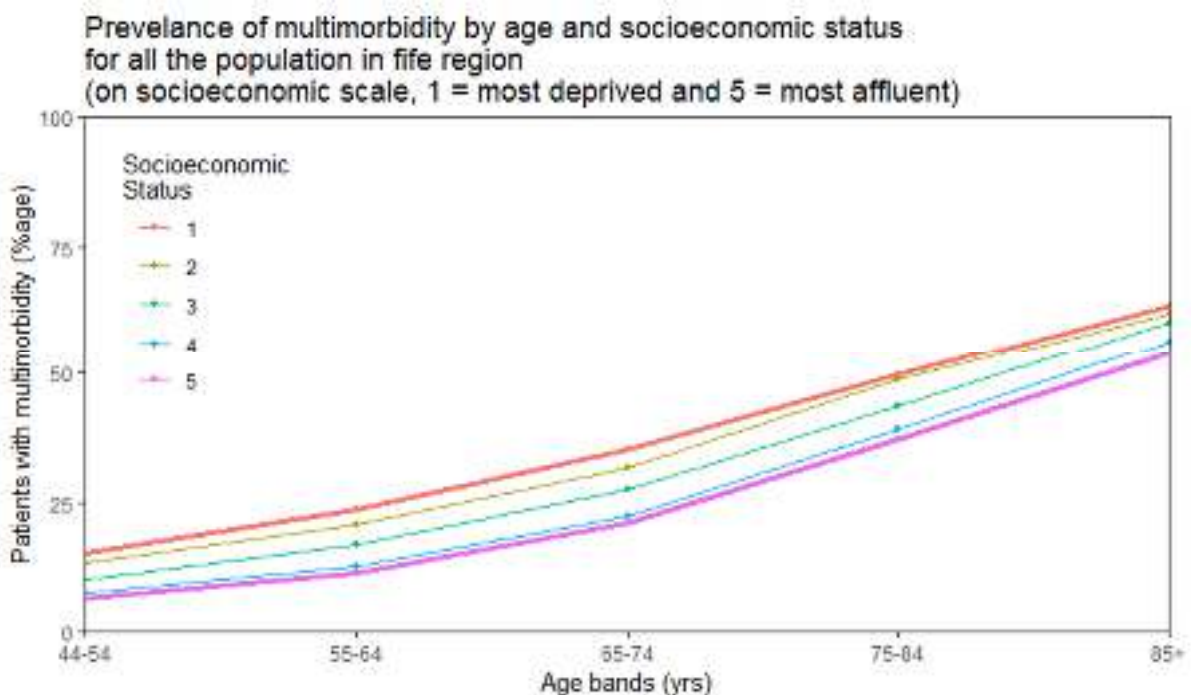
The most commonly occurring clusters of conditions for multimorbidity (patient has at least both conditions mentioned) and complex multimorbidity (patient has at least all 4 conditions mentioned) were calculated. Multimorbidity was explored for all the 31 conditions, however, due to computational complexity the complex multimorbidity were only explored for the 20 most commonly occurring single conditions.

Results

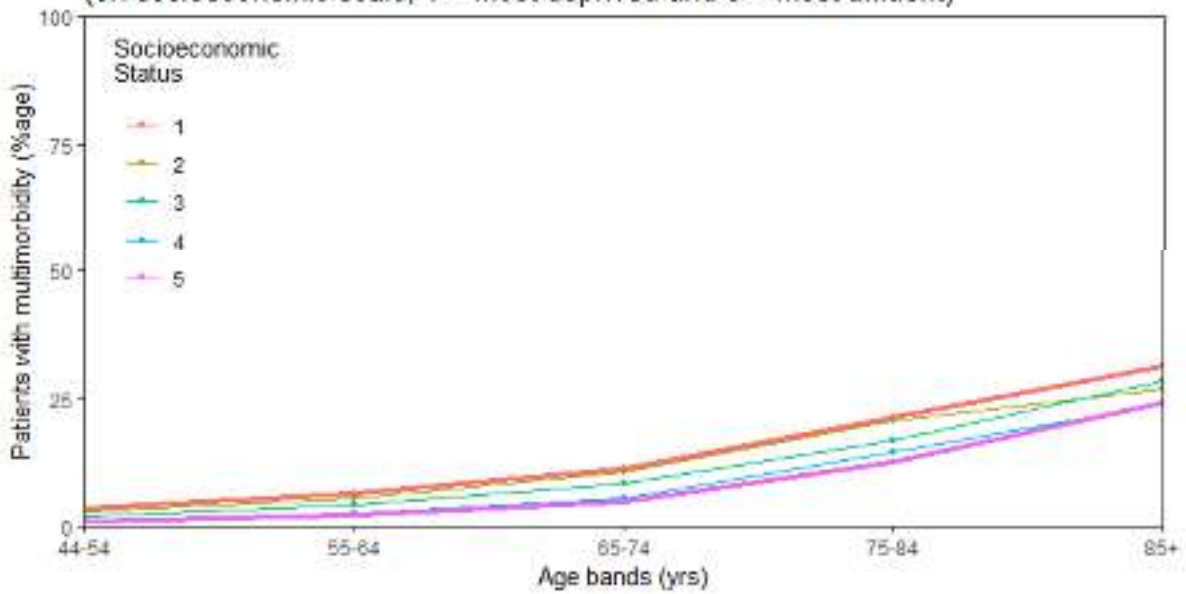
There were a total of 156,292 people aged 44+ included within the analysis on the 31st December 2018. Multimorbidity was present in just over 23% and complex multimorbidity in 7% of all patients. There were differences by gender and increase with age and increasing levels of deprivation (Table 1).

There were a higher proportion of people with multimorbidity and complex multimorbidity as levels of deprivation increased, ranging from 6.3 to 15.3% with multimorbidity for those aged 44-54, and ranging from 53.9 to 63.5% for those aged 85+ (see Figure 1). Complex multimorbidity also increased from 0.9% to 3.7% in those aged 44-54 and 24.2% to 31.2% for those aged 85+.

Group	Number	MM (2+)	Complex MM (4+)
All patients	156,292	36,201 (23.16%)	11,449 (7.33%)
Males	73,604 (47.1%)	16,539 (22.47%)	5,272 (7.16%)
Females	82,688 (52.9%)	19,662 (23.78%)	6,177 (7.47%)
Age band 44-54	45,853	4,791 (10.45%)	968 (2.11%)
Age band 55-64	43,268	7,230 (16.71%)	1,747 (4.04%)
Age band 65-74	37,263	10,038 (26.94%)	2,936 (7.95%)
Age band 75-84	22,101	9,543 (43.18%)	3,725 (16.85%)
Age band 85+	7,807	4,599 (58.91%)	2,073 (26.55%)
SIMD 1 (most deprived)	25,086	7,172 (28.59%)	2,429 (9.68%)
SIMD 2	32,846	8,771 (26.7%)	2,922 (8.9%)
SIMD 3	34,593	8,024 (23.2%)	2,570 (7.43%)
SIMD 4	31,941	6,379 (19.97%)	1,871 (5.86%)
SIMD 5 (most affluent)	31,826	5,855 (18.4%)	1,657 (5.21%)
SIMD1 and age 44-54	8,195	1,255 (15.31%)	302 (3.69%)
SIMD1 and age 85+	1,160	737 (63.54%)	362 (31.21%)
SIMD5 and age 44-54	8,772	555 (6.33%)	76 (0.87%)
SIMD5 and age 85+	1,634	881 (53.92%)	395 (24.17%)

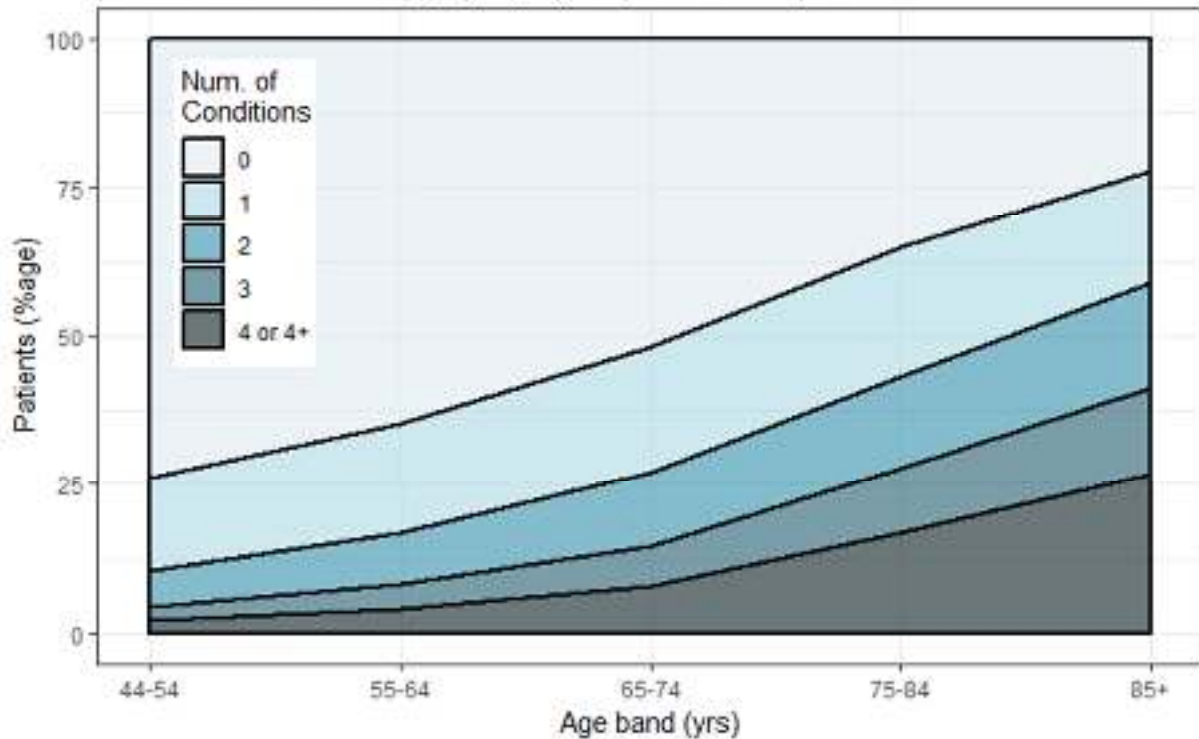


Prevalence of complex multimorbidity by age and socioeconomic status for all the population in fife region
(on socioeconomic scale, 1 = most deprived and 5 = most affluent)

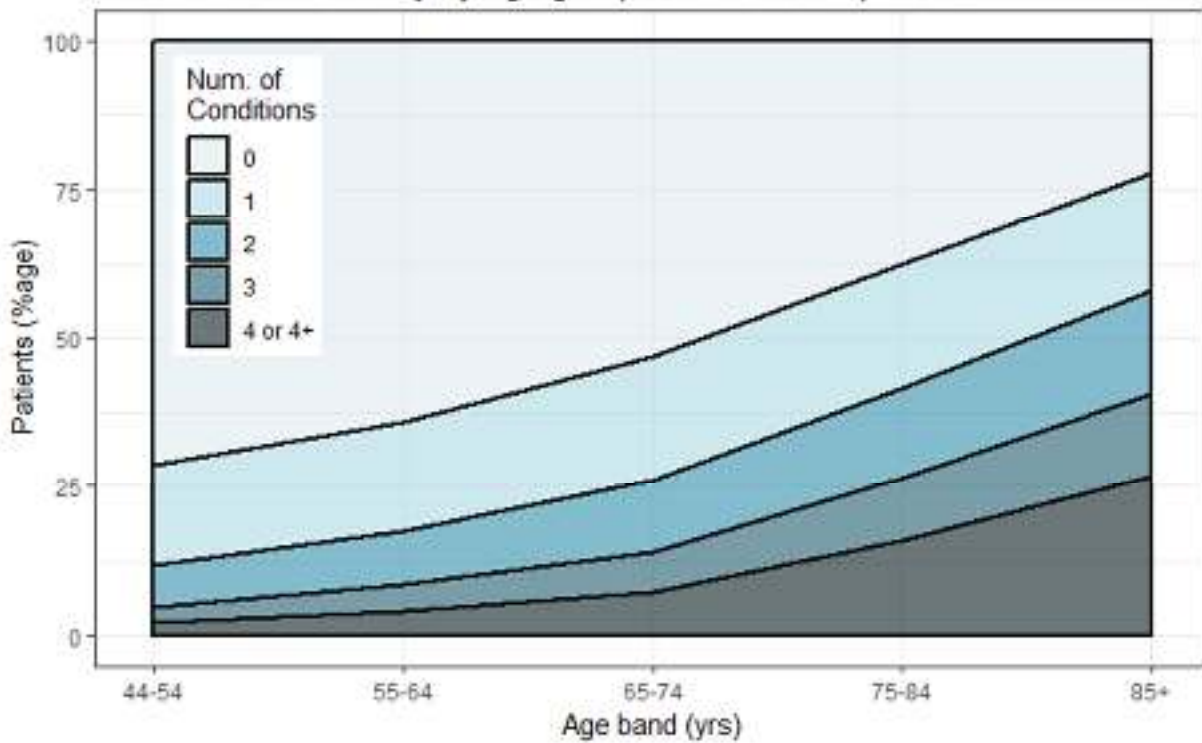


The proportion of patients with the number of conditions was calculated and is shown in the following figures for all people in Fife, females and males.

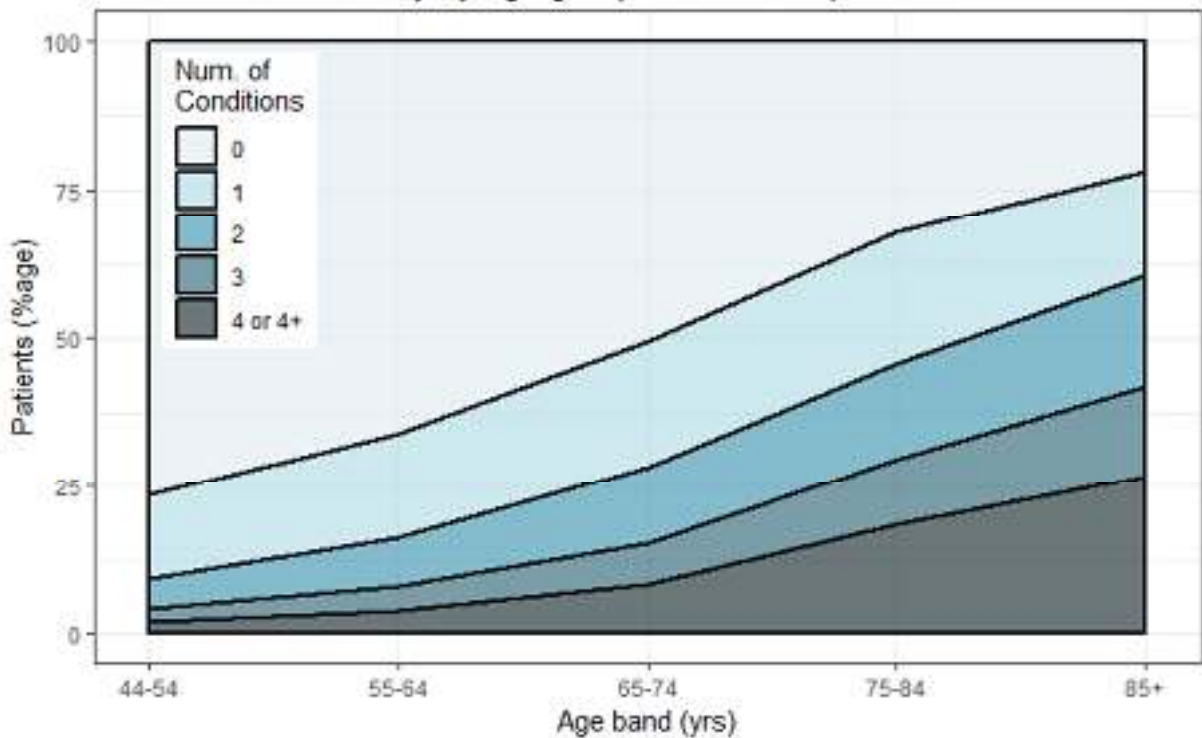
Elixhauser comorbidity by age group for all fife patients



Elixhauser comorbidity by age group for female life patients

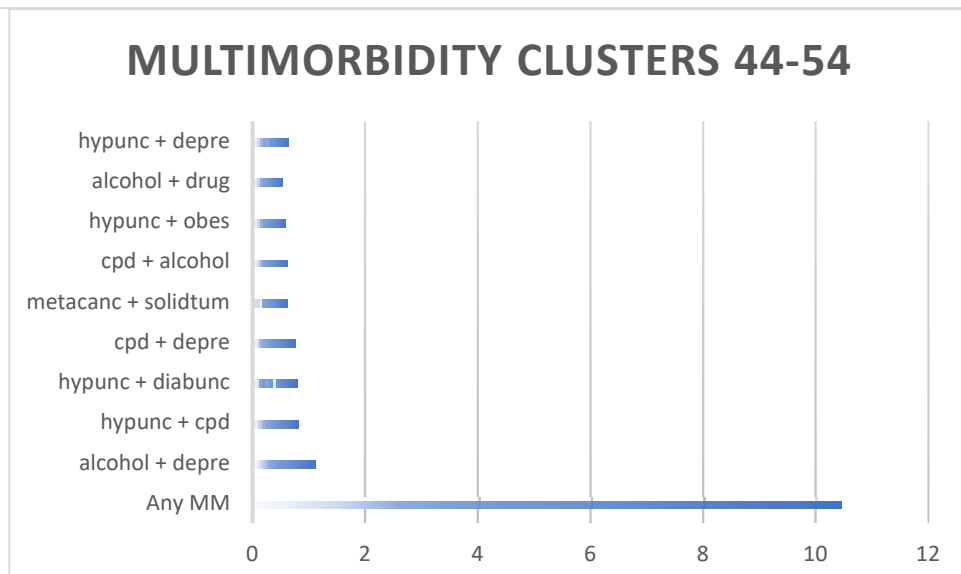
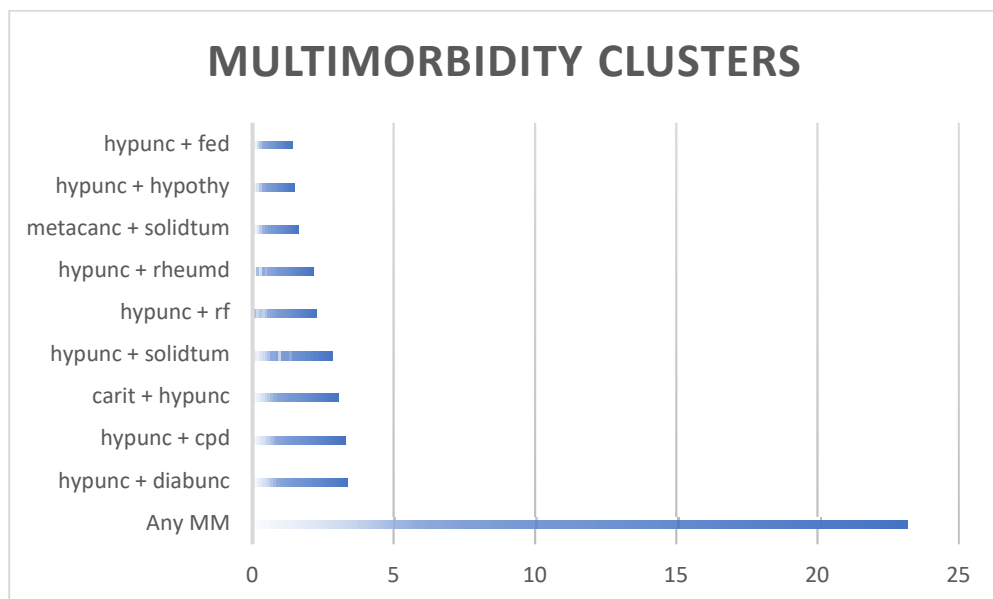


Elixhauser comorbidity by age group for male life patients

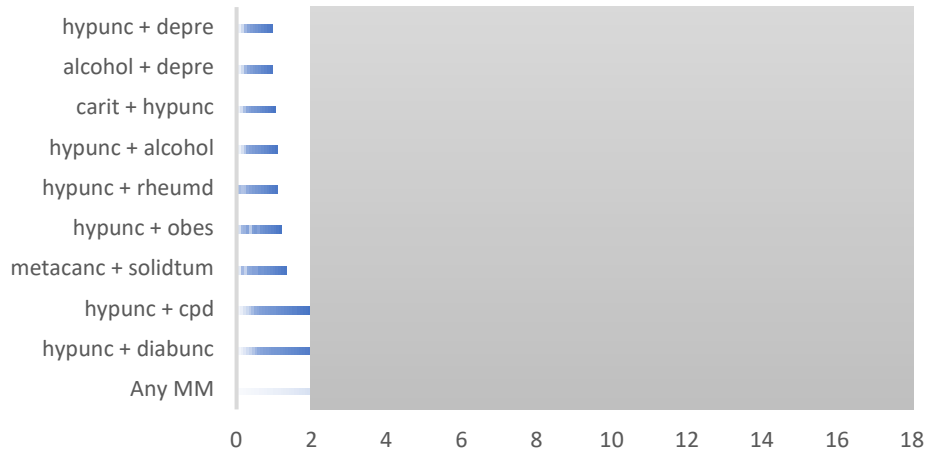


The most commonly occurring clusters of two diseases were calculated for the population and also each age group. Patients may be counted in more than one cluster (if they have more than two conditions) and the data for the top 10 clusters are shown below. Please note the scale for each graph may be different.

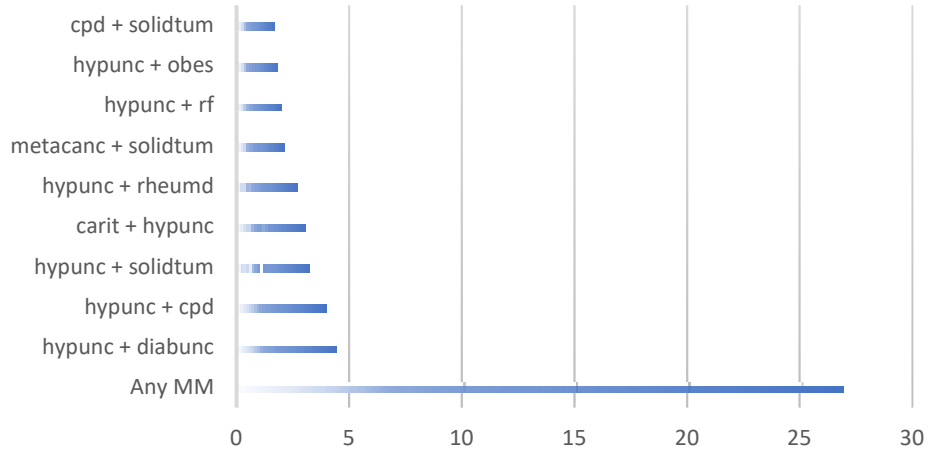
The abbreviated conditions are as below carit - cardiac arrhythmias; diabunc - diabetes, rheumd - rheumatoid arthritis/collaged vascular disease; alcohol - for alcohol abuse; rf - renal failure; hypunc – hypertension unconditional, hypothy - hypothyroidism; depre - depression; ond, for other neurological disorders; chf - congestive heart failure; fed - fluid and electrolyte disorders; pvd - peripheral vascular disorders; obes - obesity; valv - valvular disease; dane - deficiency anaemia; metacanc -metastatic cancer; drug - drug abuse; pcd - pulmonary circulation disorders; ld - liver disease; psycho – psychoses.



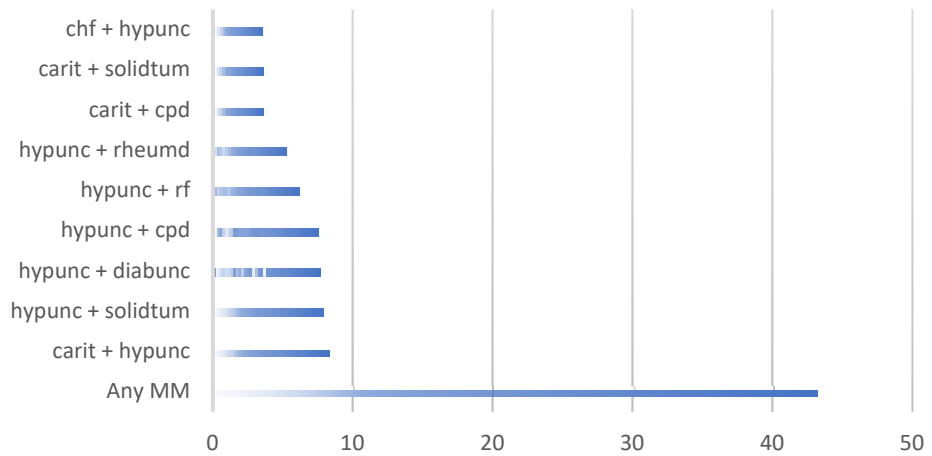
MULTIMORBIDITY CLUSTERS 55-64



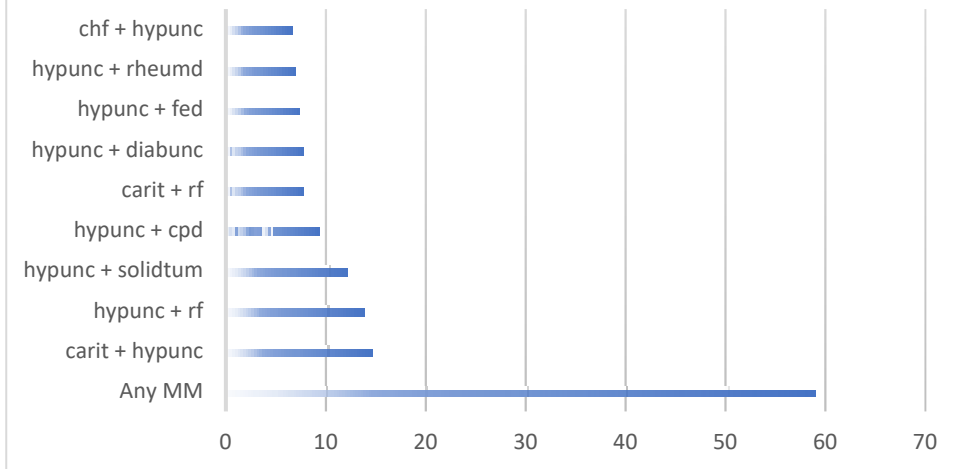
MULTIMORBIDITY CLUSTERS 65-74



MULTIMORBIDITY CLUSTERS 75-84



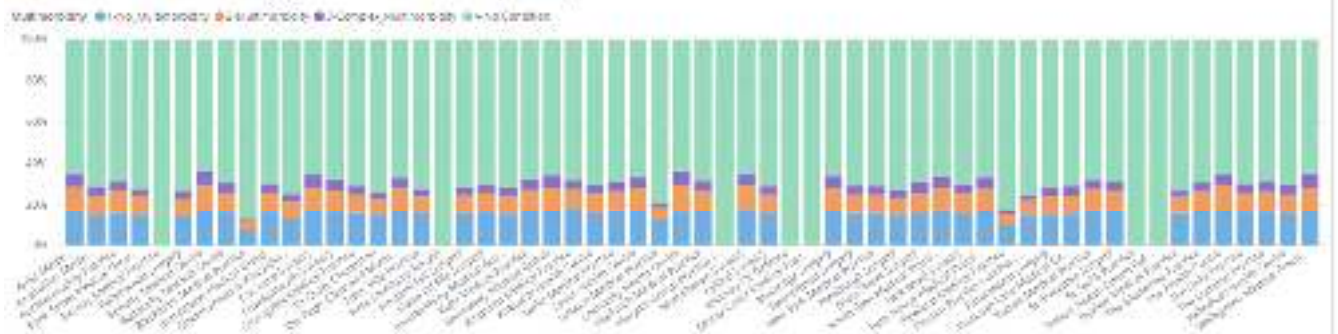
MULTIMORBIDITY CLUSTERS 85+



Practice level data Analysis

Dashboard data

Repartition of Multimorbidity by Practice in Fife (>50 patients)



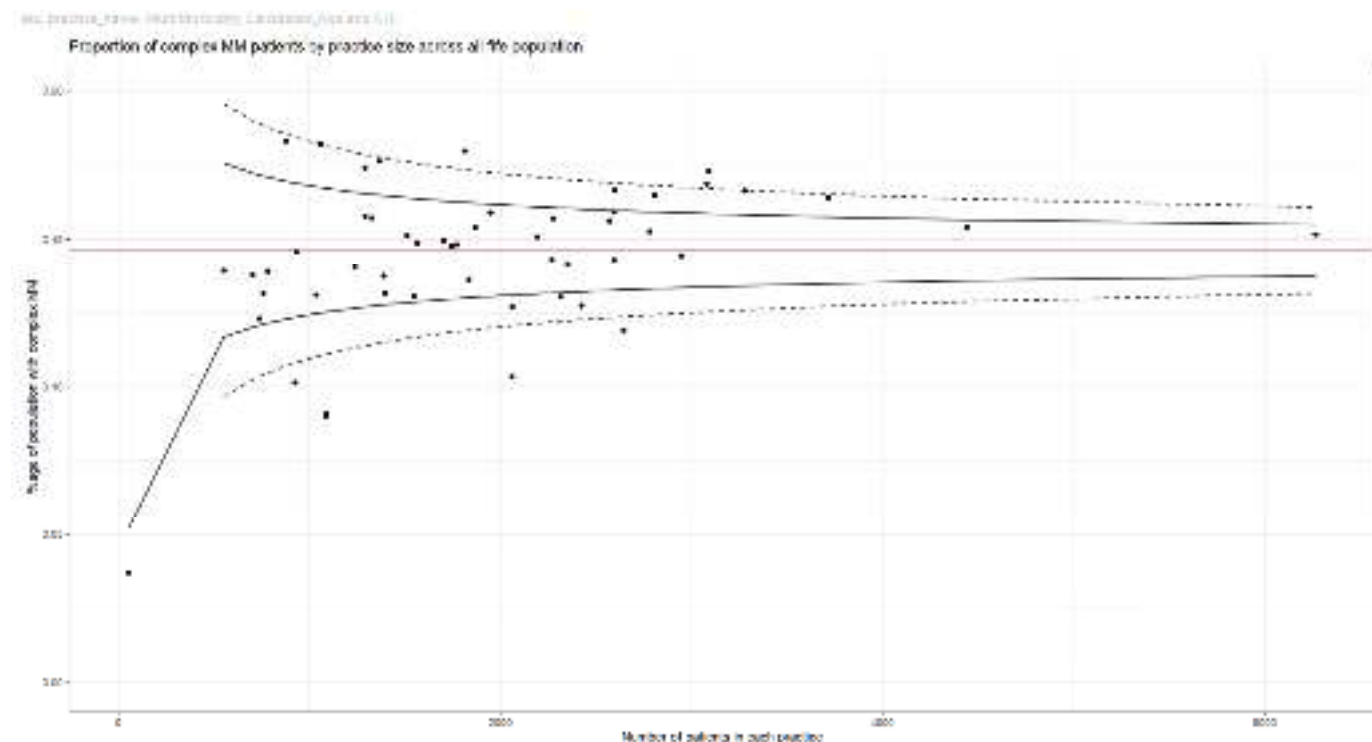
Sp. Name	1-No Multimorbidity	2-Multimorbidity	3-Complex Multimorbidity	4-No Condition	Total
1-18	4581	474	42	4758	8555
1-19	2999	708	267	3974	6688
1-20	2772	2200	431	2403	4504
1-21	4919	3006	289	4893	8007
1-22	2044	955	174	2467	3180
1-23	3011	891	291	2191	3193
1-24	1862	710	424	1261	2257
1-25	1874	412	581	587	1454
1-26	81	512	89	84	656
Tot	32281	11964	1805	74813	112053

Sp. Name	1-No Multimorbidity	2-Multimorbidity	3-Complex Multimorbidity	4-No Condition	Total
1-18	2752	728	710	4567	8257
1-19	2871	2007	45	2184	5067
1-20	4911	2617	789	4214	8531
1-21	4250	2011	45	1374	5580
1-22	124	218	729	4190	4551
1-23	2700	2772	700	2242	5614
1-24	1814	941	787	1181	3623
1-25	471	402	182	1241	1886
1-26	874	214	701	761	1850
Tot	2010	2112	1800	11327	15209

Sp. Name	1-No Multimorbidity	2-Multimorbidity	3-Complex Multimorbidity	4-No Condition	Total
1-18	4164	1891	428	7000	12483
1-19	4272	2741	1261	12206	19480
Tot	8436	4632	1589	19206	33863

Variability Analysis

Control Chart with population registered in a Practice in Fife using Elixhauser comorbidity index



4. SUMMARY OF CHALLENGES

This project incurred many challenges throughout its duration. The most significant challenge was an underestimation of the developmental phase that was required for creating an information technology and management infrastructure for NHS Fife. The original project proposal was for a period of 12 months however, as detailed in previous sections of this report, the development and planning of this infrastructure required more time and resources than originally anticipated. A summary of the different challenges in developing and creating this infrastructure are provided below:

4.1. IT challenges with NHS Fife primary care software system

As described in Section 2.1, once the project commenced, it became evident that the version of EMIS Web available in NHS Fife GP practices was not compatible and was not suitable to provide the capability to extract large amounts of data on a routine basis. Therefore, a new solution for data extraction had to be developed by Albasoft, which cost the project time and unforeseen resources (e.g. time for contractual agreement and sourcing of funds for Albasoft services).

The second IT challenge was how the data would travel. Developing the data flow was difficult and required significant research and discussion with stakeholders and data governance experts. Developing the data flow also had a significant impact on the budget and timeline. For example, we identified that a staging server needed to be purchased for NHS Fife eHealth, which was not considered in the original costing of the project, and further personnel time and resources were required to work on setting this up within eHealth.

4.2. Governance challenges

Data governance was a critical part of developing the process for how data would travel in the ELeCtra infrastructure. The Information, Governance and Security team in NHS Fife, and HIC team members were instrumental in advising on the governance that ELeCtra required, and worked closely with the project team to ensure that we identified all of the required governance and obtained the required sign-offs and approvals. In particular, due to the political climate around the new GP contract, there was a lack of clarity on who needed to sign-off on extracting data from the practices - the practices themselves or the health board. The complexity of the data flow and the variety of stakeholders interacting with the data led to a complex set of approvals that the project required (as described in section 2.1.2).

4.3 Personnel and contractual challenges

The project suffered significantly from the long-term sickness absence of the appointed Research Assistant, funding re-allocation and contractual delays to cover this absence, and contractual changes as a result of the implementation of the no-cost extension to the project.

There were also significant delays in getting various project contracts in place, including: delays in appointing the replacement qualitative researcher, and the changes to her role, and also significant delays in getting the funding contract in place between NHS Fife Endowment Funds and the University of St Andrews, and between Dundee (HIC) and St Andrews.

5. Budget challenges

The project faced significant budgetary challenges, in part due to the additional time and resources required for the developmental phase of this project, and in part to unforeseeable circumstances (sickness absence, contractual delays). There were several budgetary amendments required, including adding the cost of the server and Albasoft's services, and reducing the funding for HIC's services as a result. The originally appointed Research Assistant was on long-term sickness absence, and the University policy is that this type of absence is covered by the research grant, so we were unable to

recruit someone else from the grant, and had to rely on the School to support absence cover. The amendments to the original budget for the aforementioned services and resources also resulted in a lack of funding to extend the Programme Manager role beyond the first 12 months.

6. Other challenges

There were significant impacts caused by the delay to the overall infrastructure development. These included the engagement of GP practices to the ELeCtra project in terms of consenting to take part in sharing of their data. Initial engagement with practices was made early in developmental discussions, however due to the delay in the development and implementation of the data flow infrastructure and the lengthy process of gaining appropriate governance approvals, many practices disengaged with the project. The timing and impact of the COVID-19 pandemic additionally impacted on the team's ability to re-engage and recruit further practices.

6. DISSEMINATION AND KNOWLEDGE TRANSFER

Continual knowledge exchange and dissemination was conducted with a variety of individuals and groups throughout this project, discussing and presenting the development of the ELeCtra LHS infrastructure.

Feedback and discussion was obtained from:

- Members of the Public Advisory Group established by the University of St Andrews School of Medicine
- Clinical academic colleagues within the School of Medicine
- Academics, clinical professionals, NHS Fife and Fife Health and Social Care Partnership stakeholders in both informal meetings and discussions and through formal oral and visual presentations of the project at events including: - the annual meeting for academic Primary Care in Scotland (ADEGS 2019, 2020), NHS Fife Research Governance Meeting (Mar 2019), NHS Fife Information Governance and Security Meeting (Mar 2019), East Region Innovation Meetings (Oct 2019, Feb 2020)

7. IMPLICATIONS & FUTURE DEVELOPMENT

Roll-out of infrastructure & long-term management

- NHS control

- Need to get future investment for NHS Fife to manage this dataset in their server long-term (personnel resources, capability for analytics and reporting)

Endowments

Health Innovations South-East Scotland(HISES)

- ELeCtra Oversight Group up and running to review proposals
- further recruitment of NHS Fife practices to link their data and development of a report dashboard for their use.

APPENDIX

HIC 'SAFE HAVEN'

'Safe Havens' provide robust controls and safeguards to enable the secure transfer of sensitive data into a highly secure environment, where it can be stored, manipulated and analysed by approved data users. De-identified data are not released to data users for analysis on their own computers but are instead placed on a server within the Safe Haven, where the data user is given secure remote access to carry out their analysis. Individual-level data cannot be removed from the Safe Haven by data users. Only outputs from analyses may be removed (e.g. reports, summaries, aggregates, graphs etc.). Output results are reviewed and, once verified as not containing individual-level data, emailed to the data user.

HIC is a non-profit University of Dundee research-support unit located in the Medical School at Ninewells Hospital. HIC has been working closely with NHS Fife for the past 10 years to provide secure hosting and provisioning of NHS Fife clinical data to support research, audit and improvement initiatives. HIC has implemented a remote access 'Safe Haven' environment, which has been in operation for over 5 years. In this model, no identifiable data will leave the NHS servers and the de-identified data from ELECTRA will only ever be used within the HIC Safe Haven for approved projects.

HIC holds internationally recognised data security accreditation (ISO27001), undergoes external audit twice annually, and is overseen by the HIC Information Governance Committee with NHS Fife membership.

