

Hidden in plain sight: Identification of people with ‘complex lives’ in General Practice using a data-driven approach

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Abstract

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It is commonly observed in General Practice that there is a group of patients whose lives are characterised by multiple health and social issues, are prescribed multiple psychotropic and analgesic drugs and attend frequently. This group with 'complex lives' are intuitively known by clinicians, but there are challenges in easily identifying these patients from GP records. A collaboration of GPs from across Devon met to explore this group of patients who frequently attend the practice but may be 'hidden in plain sight'. Quality improvement methods were used including a combination of reflective practice, structured interrogation of electronic primary care records and the use of data analysis techniques. Using the 95% centile cut off for both number of appointments and drug groups a cohort was identified in each practice of approximately 2% of the population. Arbitrary cut off values were not found to be as helpful when comparing across practices. Qualitative note review identified consistent themes such as social adversity, chronic pain and mental health problems, many of which were not coded. This cohort was found to have a higher use of urgent appointments and often consulted multiple GPs. This is a novel data driven approach which uses attendance and prescribing data as opposed to clinical codes to identify a manageable sized group in each practice, the majority of whom could be seen to have 'complex lives' but are 'hidden in plain sight'. The authors suggest this replicable approach can be used to identify a group of patients from practices within a primary care network who may benefit from a multi-disciplinary approach, social and prescribing interventions and wellbeing support.

Introduction

It is commonly observed in General Practice that there is a group of patients whose lives are characterised by multiple health and social issues, and who bring about a profound emotional response in GPs. It is, almost by definition, hard to define what characterises such patients. In the past the term 'heart sink' was used in perhaps the first practice based study of such a group (Thomas O'Dowd, 1988). The more technical terms 'somatisation' and later medically unexplained symptoms (MUS) were applied, but O'Dowd's original group also included individuals with chronic depression and anxiety. The group seems to include those with diagnoses of fibromyalgia and other chronic pain syndromes, as well as mental health diagnoses; they often have complex social circumstances and past trauma; and have patterns of health care which include high levels of appointments (leading to term frequent attenders) and the prescription of multiple psychotropic drugs.

This group of patients often place a considerable burden on both health care budgets and GP time (Anna Cassell, 2018) with 1 in 6 to 7 of consultations being with the top 3% of attenders (R D Neal, 1998). Research has shown a strong association between frequent attenders and polypharmacy (Peter Vedsted P. F., 2004), with 27% of all prescriptions being attributable to the top 10% of attenders in one study (Peter Vedsted H. T., 2004).

Interventions to address somatisation with direct psychological work are only marginally effective (Olde Hartman, 2017) and it seems reasonable to hypothesise that their persisting unmet needs are driving their high attendance and prescribing and that this is, in part, due to

the current medical model of consultations and medicine inadequately managing the biopsychosocial complexities present.

The group of individuals with 'complex lives' are intuitively known by clinicians but there are challenges in developing models to identify them. Coding into the GP electronic health record is variable particularly for non-specific symptoms (Jordan 2004, Tulloch 2020, de Lusignan 2005, Khan 2010). Use of empirical models to find this group has limitations and various approaches have been taken over time such as using symptoms, diagnosis, social problems, trauma and clinical activity such as attendance or prescribing. None alone appears effective, although searches for both frequent attendance and polypharmacy showed potential to identify individuals who may be missed if not coded diagnostically. Pioneering work by GPs such as John Fry used practice led data analysis, and later generated research questions to drive quality improvement and evidence based best practice (John Fry, 2007). More recently, activity data contained in the electronic health record (EHR) and population health management (PHM) techniques have been used as a means of identifying groups of patients with particular needs who may need something different clinically (NHS England, 2022).

A group of GPs met to explore these patients with 'complex lives' who frequently attend general practice, but may be hidden in plain sight. These GPs noticed they would frequently recognise individual patients with these characteristics and that these patients commonly evoked a strong emotive response but were hard to identify as a patient cohort. This project aimed to find a way of identifying this challenging/demanding/difficult/rewarding/amorphous/hidden patient cohort, with the objective being to understand their characteristics and needs as a population group. We wanted to inform the work of practices and Primary Care Networks which have a range of new workers such as pharmacists, coaches, navigators and social prescribers who might have a role alongside GPs. A data-driven approach was developed to identify this complex population which have been described in the medical literature qualitatively but whom do not have precise reliably coded diagnostic labels.

The results could be used to develop a population health management approach to support whole person care in order to improve health and wellbeing outcomes and healthcare interactions as well as satisfaction for both patient and clinician.

Method

The quality improvement methods used included a combination of reflective practice, structured interrogation of electronic primary care records and the use of data analysis techniques. An iterative approach emerged which is described below.

Setting

GPs from four practices in East and Mid Devon worked collaboratively on this analysis. Two practices are in the large seaside town of Exmouth and two in the towns of Collumpton and Tiverton which also cover a rural population. Three of the four practices has a population of around 12,000 with large multidisciplinary teams of clinicians, one has a smaller population with a smaller clinical workforce. Final comparative analysis involved only three of the four

practices due to the need to share complex searches via an organisational sharing group in the SystmOne clinical systems.

Stage 1 – Initial searches

Four GPs from different practices worked with a data analyst to create and run clinical system searches in order to identify the cohort of patients with complex lives. Searches for specific coded diagnoses such as fibromyalgia and chronic pain showed low numbers in keeping with GPs own experience that the diagnosis and coding of these conditions either occurred late in a healthcare journey or not at all. It was hypothesized that limiting the searches to only coded diagnoses would fail to identify many patients in this group and that searches based on clinical activity may be more productive. As both frequent attendance and polypharmacy had been show to be characteristics of this group searches combining both were tested.

Initially attempts were made to look at healthcare attendance in the broadest sense to include not only GP clinical appointments but out-of-hours reports, emergency department (ED) attendances, hospital referrals and missed appointments. However it became clear that there was no consistent coding of these healthcare attendance events within and across practices. In one practice where the data was available a notes review of this this group with frequent attendances did not appear to have increased ED or out of hours attendances.

The initial search was set to include the top 5% of attenders and 3 or more prescriptions of psychotropic medication in the last 12 months.

Stage 2 – Refining Searches

Medical notes of the initial cohort were reviewed briefly with the aim of assessing whether the individuals coming up 'fitted' into the perception of this 'complex lives/hidden in plain sight' group. The searches were refined to exclude under 18 year olds. The appointments were refined per practice to only show those appointments with doctors and nurse practitioners, in order to include few individuals attending mainly for chronic disease monitoring. This process required knowledge of each practice set up and staffing. The GPs worked with the data analyst individually to fine tune searches to reflect the differences in practice organisational appointment architecture, prescribing and data recording. The process required the appointment data to be exported into an excel spreadsheet, the data to be cleaned per practice dependent on appointment and clinician type and then the use of a pivot table using the rota type and clinician type broken down by NHS number count in order to identify the highest attenders for these appointments.

This allowed the appointment data to reflect acute and routine clinical contacts with a GP or nurse practitioner including telephone, face to face and e-consult (in some cases). It was agreed to exclude all protocol-driven structured long term condition reviews such as INR or blood monitoring, health care assistant appointments, treatment room nurse appointments and long term contition follow up appointments. Searches were created using practitioner name and appointment and clinic type from the clinic rota data. There were some data limitations such

as how the e-consult appointments were captured in the clinical system and whether nurse practitioners also did treatment room and routine long term condition reviews.

Adjustments were made to the prescribing search. The aim was to create drug groupings often used for different types of pain or relief of mental distress. Psychotropic drugs categorised into twelve groups (see appendix) representing 'use types' and certain drugs were excluded such as anticonvulsants which are usually used for epilepsy and only rarely for mood stabilisation. The drug groupings per GP software system varied so searches for specific drugs were created in each clinical system as opposed to 'classes of drugs'. The drug reports were tailored to count the number of classes of drugs a person has been prescribed as opposed to the total number of drugs.

The 'complex lives' cohort was created by finding the patients who sat both within the top 5% of frequent attendance and the top 5% of drug groups prescribed.

By combining the top 5% of attenders with this drug search, a smaller refined cohort who had a higher number of different classes of psychotropic drugs prescribed was found. An organisational sharing group was set up on SystmOne to facilitate shared searches across three of the four practices who used the same clinical system. Using these refined search criteria each GP identified a cohort of between 25 and 50 patients at their practice.

Stage 3 – Notes Analysis & Reflections

Each of 4 GPs undertook a detailed notes review of all patients in the refined cohort (30-50 per practice). The aim of the note review was to do a detailed analysis of the patient health record, review consultations, letters, clinic attendance, emergency attendance and diagnostic codes, social issues and any noted life events. The aim was to get an overall sense of the medical and social context of the patient. This was intentionally 'unstructured' to allow iterative identification and collation of all relevant themes. Each GP presented their analysis of the note reviews to the group, and they highlighted key themes that had arisen.

Stage 4 – Developing a replicable data-driven approach

In order to create a replicable process that could be applicable to other practices and across primary care networks (PCN) it was agreed to create and share a set of final standardised searches. Firstly a standardised set of drug searches were created to reflect the twelve drug groups listed. Secondly equivalent clinical appointment data was collected to allow direct comparison between the four different practices. The 'complex lives cohort' is identified by finding the top 5% of attendance and prescribing groups and finding those who were within the two groups.

Results

The final standardised searches were created and run at the three practices with SystmOne clinical system only, as the fourth practice had a different GP IT system which could not run the same search. This allowed the creation of the cohorts. The three surgeries gave the following results:

The top 5% attender cohort attended above a different threshold number of appointments in each practice ranging from 16 to 26. The top 5% of people with the most number of drug classes prescribed also had variation between practices – varying from five to six classes. The ‘complex lives cohort’ created by using the 5% attenders and drug classes yielded a manageable size group to analyse varying from 1.6 to 2.2% of practice population (Table 1).

Table 1: 95th Centile Cut Off

		95th Centile based Cut Off					
		Practice A		Practice B		Practice C	
Metric		Cut Off	Patients	Cut Off	Patients	Cut Off	Patients
List Size >= 18 yrs			12539		4445		9247
Appointments		>=26	637	>=16	257	>=17	529
		<26	11902	<16	4188	<17	8718
Appointment Cohort as % of Practice			5.1%		5.8%		5.7%
Drugs		>=5	987	>=6	315	>=6	481
		<5	11552	<6	4130	<6	8766
Drug Cohort as % of Practice			7.9%		7.1%		5.2%
Appointments AND Drugs			202		99		144
			12337		4346		9103
Combined Complex Cohort as % of Practice			1.6%		2.2%		1.6%
Age	Mean		60.8		52.4		57.9
	Median		60		54		56
Gender	% Female		72.8%		82.8%		77.8%
	% Male		27.2%		17.2%		22.2%

As a comparison, an alternative analysis was done using a set number of appointments (12 or more per year) and drug class number (3 or more drug classes) as an arbitrary cut off. Table 2 below shows how this arbitrary cut off led to a frequent attender range of 11-23% of the total practice population – due to the difference in the practices ‘highest’ and ‘lowest’ number of attendances per year. The percentage of patients on 3 or more classes of psychotropics was broadly similar across all three practices. The disadvantage of this approach is that it captured a varying number of patients in each practice ranging from 6.9-11.7% of their practice populations (table 2).

Table 2: Arbitrary Cut Off

Metric	Cut Off	Practice A	Practice B	Practice C
List Size >= 18 yrs		12539	4445	9247
Appointments	>=12	2967	479	1024
	<12	9572	3966	8223
	Appointment Cohort as % of Practice	23.7%	10.8%	11.1%
Drugs	>=3	3211	1458	2555
	<3	9328	2987	6692
	Drug Cohort as % of Practice	25.6%	32.8%	27.6%
Appointments AND Drugs		1467	348	640
		11072	4097	8607
	Combined Complex Cohort as % of Practice	11.7%	7.8%	6.9%
Age	Mean	60.5	55.3	61.1
	Median	62	56	62
Gender	% Female	67.1%	75.6%	67.5%
	% Male	32.9%	24.4%	32.5%

Use of the 95th centile to create the combined complex cohort resulted in a group with a mean age of over 50 years (range 52-60 yrs) and an approximately 3 to 1 ratio of females to males. Using an arbitrary cut off generated a mean age of over 55 (range 55-61 yrs) and a lower ratio of males to females.

Note review themes of complex lives cohort

Several themes were identified from the qualitative note reviews. Social adversity – both past and present – were identified including safeguarding concerns, social work input, domestic violence, suicide of relatives, alcohol and prescription and non-prescription drug abuse, drug overdose, single parenting, low literacy and adverse childhood events.

The most commonly described (and often not coded) diagnoses related to consultations were for pain, fatigue, gynaecological and mental health issues. Musculoskeletal, abdominal, pelvic were the commonest presentations of pain. It was noted that only a minority of those with chronic pain or chronic fatigue were coded as having fibromyalgia or chronic pain.

An analysis of the notes to look at appointment requests identified that this population had a higher number of same-day and urgent appointments and often consulted with several different GPs as opposed to regular attendances for routine planned care with one clinician.

The GPs used the themes to create three composite patients reflecting typical individuals identified in our Complex Lives cohort (see Box 1). These illustrate the variation with the overall group: more elderly individuals who had a number of co-morbidities but analysis of reasons for attendances showed that their appointment tended to relate to low mood, anxiety and chronic pain; younger individuals with fibromyalgia and chronic pain presentations more classically associated as 'heart sink'; and those with longstanding adversity and multiple physical diagnoses alongside recurrent episodes of self-harm, also relatable to the 'heart sink' label.

Box 1. Typologies of complex lives hidden in plain sight

Patient A is female, aged 52 with coded diagnoses of Fibromyalgia, Chronic Pain and Chronic Fatigue. She attends frequently with multiple symptoms which vary between consultations. She has experienced social adversity such as housing issues, loss of employment, debt, family fragmentation. The GP recognises Patient A as a complex, challenging or heart sink patient.

Patient B is male or female, and aged 74. He/She has a lifelong history of frequent attendance at their current and past practice and consults with pain, anxiety and depression. They may have experienced adverse social circumstances (bereavement, domestic abuse and social isolation). Patient B has been diagnosed with between 2 and 5 long term conditions but attendances at the practice are triggered by low mood and pain and many appear to be driven by underlying anxiety. The GP may not recognise this patient as being within the Complex Lives Cohort.

Patient C is a woman or man aged 27. They present frequently with musculoskeletal, abdominal or gynecological pain. They do not have coded diagnoses of chronic pain or fibromyalgia. There are some historical safeguarding concerns in the notes. They have a history of self harm and overdose. They are not usually coded as having depression or anxiety. The GP intuitively recognises Patient C as complex or 'heart sink' and is aware they attend frequently with multiple differing symptoms.

Discussion

New Findings

The quality improvement project generated a novel search method and new insights into the nature of the population with high rates of attendance and prescribing. Our data-driven approach uses appointment attendance and prescribing as opposed to clinical codes to identify a manageable sized group (1.6-2.2% of each practice population) the majority of whom could be seen as having complex lives but are 'hidden in plain sight'. Basing searches on clinician (prescribing) and patient activities, instead of coded diagnosis, revealed a wider group of people most of whom do not have a coded diagnosis such as 'chronic fatigue', 'chronic pain', fibromyalgia or specific mental health diagnoses. A key output of the work is the search tool in the appendix.

The deep-dive notes analysis identified that within this 'complex lives cohort', alongside the more classic group of individuals with fatigue, pain or self harm, there are a group of frequently attending patients who may not immediately be recognised by GPs as being complex or challenging, despite having similar levels of healthcare use and prescribing patterns. This group appears to share the characteristics of adverse social circumstances and

have a combined burden of physical and mental health problems leading to health care attendance resulting in high levels of prescribing of psychotropic medication. It is likely that this quietly re-attending population may also have unmet needs.

The current reliance on same day 'duty' surgeries may be worsening health outcomes for this cohort and a change may be welcomed by GPs who can find this group of patients difficult emotionally.

Relation to literature

Clinicians have tried various ways to identify and improve care for challenging or high need patient groups. Early practice level discussion and review of written notes led to a recognition of the 'heart sink' patient (O'Dowd, 1998). The adoption of electronic health records brought the ability to search for particular diagnoses thought to correlate with this patient group. More recently, structured PHM approaches at system and PCN level calls for clinicians to use data from the EHR and other sources to identify cohorts who may have unmet health needs. We have demonstrated another method involving groups of clinicians coming together and working on a commonly recognised problem, developing a data-driven approach to identification and working iteratively to refine and standardise an approach, with the aim of contributing to improved care at the population level familiar most familiar to clinicians – their own practice, or PCN.

This data-driven approach is a novel tool and a practical way to identify a group of people with 'complex lives'. It brings together previous approaches of clinician identified 'heart sink patients' (Thomas O'Dowd, 1998) with search strategies for frequent attendance (Peter Vedsted, 2004, Frans Smits, 2009) or polypharmacy. GPs intuitively recognised this group as frequent attenders with multiple problems and in many cases felt an emotional reaction to this group that would fit the label 'heart sink'. In many cases GPs felt a futility of the cycle of repeat attendance and prescribing and an expressed frustration about the lack of satisfaction and resolution for both clinician and patient. The people who were identified within this cohort fulfilled the participating GPs ideas about the complex lives group and identified individuals who have been illustrated in prior literature. This group is well described by clinicians but has hitherto been hard to identify within a practice cohort. The process undertaken also generated a more collective idea about the complex lives groups by identifying themes that were seen within this group. The clinicians agreed that many of those identified using this method would not have been found by searching for codes of chronic pain or fibromyalgia alone but on review of notes they clearly met a broader definition of complex psychosocial issues, pain, mental health issues and health and medication seeking for their complex lives.

Many of the cohort of complex lives patients received care from multiple different GPs, and they were more likely to get "same-day" appointment slots. This highlights that this high need group of people are having disjointed care, rather than the relational and organisational continuity of care supported by the literature. Being seen by multiple GPs is unlikely to advance holistic care and is likely to promote temporary solutions such as psychotropic prescribing, that may be detrimental to the patients' health over time. Research has shown

that group of people benefit from structure and stability and continuity of care. In those with multimorbidity (Susan M Smith, 2012) a Cochrane review found that improving prescribing and changing the organisation of care may positively impact outcomes. One Spanish study trialled a GP intervention following training in biopsychosocial, organisational and relational approaches versus normal care and found a significant reduction in attendances (Juan Angel Bellon, 2008). However, the evidence is scant, and more studies are needed.

Strengths and weaknesses

This approach brought early career GPs with an interest in primary care research and quality improvement together around a common interest, to discuss and explore new ways of identifying and addressing challenging consultations. This led to an iterative and inductive approach to the use of data and the EHR, grounded in everyday clinical practice.

Our novel method uses attendance data and prescribing as opposed to coding which is known to vary widely. The use of the top 5% of these combined groups offers a replicable approach to find the approximately 2% population in each practice that can be characterised in this 'complex lives cohort'. This is a manageable cohort size to initiate a change management project in those with the highest use of GP services and prescription for psychotropic drugs. Alternatively the approach using a specific cut off in prescribing and attendance could be used to show variation in practice need and help allocate resources. We recognise that whatever the cut off used it will always be in some ways arbitrary and we were guided by pragmatism. Also it is recognised that the search strategy missed out a group of individuals on high levels of psychotropic medication but not attending at all. Their levels of need are completely out of site of practices.

Clinicians working with a data analyst at practice level offers a mechanism for individualised search creation that can then be used to compare the attendance and prescribing activity and complex lives group between practices at PCN level.

The GP team looked at a small cohort (3 practices) within one area (Devon).

The initial idea arose from conversations between clinicians rather than being patient led/initiated/centred and was developed iteratively rather than being hypothesis driven. The data was taken from electronic health records only and did not include patients views or engagement.

Differences in IT systems between practices created significant challenges when trying to run identical searches. Only practices using the same clinical system (SystemOne) were able to directly share searches across practices. Even within the same clinical system, GP IT system searches rely on searching coded data such as diagnoses, results and prescriptions, or recorded metrics such as appointments. The 'search creation' step therefore varies between GP software systems and there is no clear way around this, leading to the need for an "as similar as possible" search approach.

Each practice had different appointment structures and variations in coding and prescribing were observed. This required the time of a data analyst to support individualising appointment data per practice such that a comparable group of appointments (clinical

reviews by GPs and nurse practitioners) were compared, however this approach allows much more meaningful data to be compared across practices. Patient contact which were by message or email, for example e-consult were not included in every practice in the analysis. These contacts were processed differently per practice with some generating an appointment which would be auditable others generating a 'task' which was hidden. Out of hours and emergency attendance were not included in the analysis.

The requirement to work closely with a data analyst to take account of different IT systems, prescribing protocols, and practice appointment architecture (even within the same IT system) impacted our ability to set up replicable reports/searches to share practices. Close working at practice level may not be easily replicable for busy clinicians.

A limitation of this work is that it did not involve patients. Notes were audited but a patient participation voice was not heard. Patient engagement is vital if this work is taken forward.

Implications for practice

Recognition of how the complex interplay of biopsychosocial factors contributes to the frequent attendance and polypharmacy observed could lead to interventions that can offer meaningful benefit to patients. This is a first step to identifying people who may have needs unmet by their current primary care services. It gives GP practices and PCN the opportunity to further understand their health and wellbeing needs so that services can be tailored to meet these needs of these needs such as a more integrated, psychosocial care system. In turn meeting these unmet needs by alternative appropriate support may reduce demand on GP services which would be better for the wellbeing of this group of patients and their clinicians.

This is a bottom-up grass roots approach as an antidote to the top down system-driven processes and PHM approaches that ICSs will be driving. It will engage clinicians in what ICSs are trying to do, give useful data to the system to describe what's important and provide useful PCN level stratification data to support individual clinicians work more collaboratively with incoming ARRS roles in a multidisciplinary way. Supporting and supervising practice social prescribing link workers, pharmacists, mental health workers, health coaches and navigators in the primary care based care of this sometimes challenge but often rewarding group will be important to retain those ARRS roles and make the most appropriate use of their skills, alongside supporting patients to sometimes be less dependant on health care that is not always effective.

Conclusion

This data-driven approach allows meaningful comparison of similar sized cohorts across different practices by analysing equivalent but not the same data from each practice. No data extraction is required, rather than search techniques and search files are shared. This would not be possible in the same way through analysis of amalgamated population health level data which requires data extraction and re-matching and would use arbitrary cut offs for values as opposed to practice centiles. This technique allows the identification and visualization of a previously known but hidden population of patients with 'complex lives'. Clinicians 'know' who these patients are but they are hard to identify. This approach offers a new way of identifying this group that moves away from reliance on clinician dependent coding practice by combining attendance and prescribing data. It allows data to be drawn from individual practice systems that can be compared meaningfully across practices. This information can help shape individual practice level interventions and or PCN approach to health and wellbeing services. This technique can also be used to identify a population of people with 'complex lives' and unmet needs which could form part of a population health management strategy for PCNs.

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Appendix 1 Drug Groupings

1	Tricyclics	Amitriptyline, Nortriptyline
2	Antipsychotics	Amisulpride, Aripiprazole, Chlorpromazine, Haloperidol, Olanzapine, Paliperidone, Quetiapine, Risperidone, Sulpiride
3	Short Acting Benzodiazepines	Diazepam, Lorazepam
4	Duloxetine	Duloxetine
5	Gabapentinoids	Gabapentin, Pregabalin
6	Sub group of antidepressants	Mirtazapine, Venlafaxine
7	Propranolol	Propranolol
8	Sleeping tablets	Melatonin, Temazepam, Zolpidem, Zopiclone
9	Trazodone	Trazodone
10	SSRI & SNRI	Fluoxetine, Sertraline, Paroxetine, Citalopram, Escitalopram
11	Lithium	Lithium
12	Opiate analgesia	Codeine, MST, Tramadol, Co-Codamol, Tapentadol, Severdol, Methadone, Fentanyl, Buprenorphine, Oxycodone, Oramorph

Appendix 2 Methodology

The data set gathered to identify patients is from a combination of reports. The NHS number and the patients age are obtained from the capitation report and this is used as the master data set which is then joined to the prescribing and appointment data sets.

The appointment query (or queries if the data returned is greater than the SystmOne limit of 30000 rows) and the prescribing queries are run and exported as comma separated value (csv) files.

The R programming script **process_complex_lives_data.R** is executed and this will combine the data sets into one csv file called **combined_complex_lives_data.csv** which can then be opened in Excel.

A synthetic dataset and configuration file has been provided to run as an example of both the data output from SystmOne and also the final output to use to identify patients.

This technique required the support of a data analyst. The authors will develop a more simplified technique using SystmOne and Excel with instructions to enable this to be replicated in other practices

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