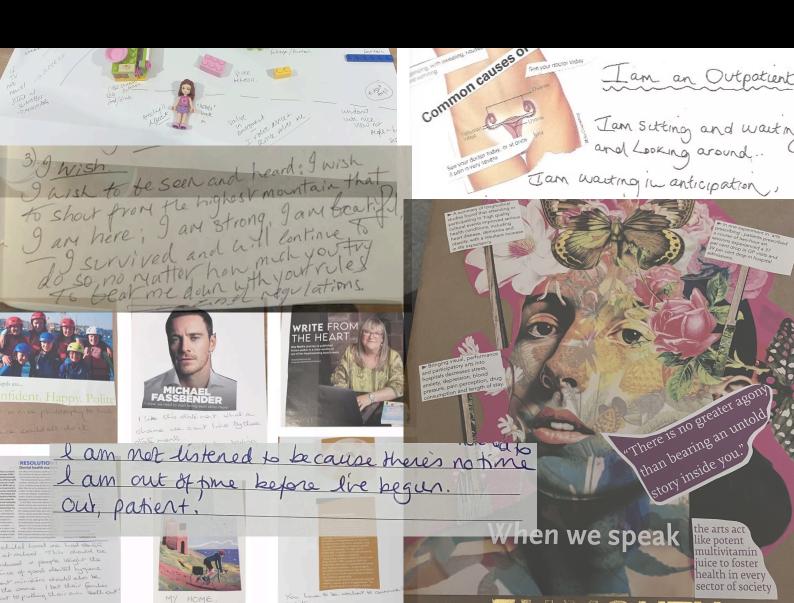


REIMAGINING OUTPATIENTS



The Reimagining Outpatients Project

This booklet is the result of phase 3 of the Reimagining Outpatients project run by Falmouth University. This phase aimed to channel creativity so that research participants gained wellbeing benefits from telling their stories as well as searching to find ways to envision future outpatient services for the benefit of our communities.

Central to this approach was the process of 'making' and how the stages of producing insight in themselves facilitate a more in depth understanding of the journey taken — for us as researchers, and for the participants themselves.

Participants were given a toolkit with weekly prompts to explore current and future outpatient provision. We held four "check-in" sessions face to face and online, and participants undertook creative journalling and writing at home. The sessions were varied; we talked, wrote, encouraged, collaged, played with lego and read poetry; we made connections.

Many of the pieces included in this booklet came from a process we used early on called 'freewriting', which helps us get away from our rational way of thinking and writing and allows us to explore things that might be surprising, interesting and new. The group was gently steered towards poetry and map-making and soon began to visualise their journeys in experiential ways.

All of our participants — with all levels of writing experience — wrote eloquently and powerfully about themselves, and I am grateful to everyone who took part for their honesty and commitment.

It is no secret that our NHS is in crisis: we heard stories both positive and negative about the outpatient experience, and outpatients are acutely aware of the stress that services are under. Part of the feedback on the transformation needed is to consider the wellbeing of our healthcare providers as well the wellbeing of outpatients. The task is a complex one. Our outpatients all agree that they want to see the heart put back into our beloved NHS.

I am an outpatient

- I am out, but not to you because you don't ask
- I am asking questions because you don't explain
- I am listening to you explain why you're running late
- I am two minutes late and fretting that you won't see me
- I am not seen by you, only shoved into boxes
- I am not able to fit into boxes any of them
- I am anyone sometimes a new persona from the wrong file on your desk
- I am sat on one side of the desk and you on the other
- I am other. You are us. I am them
- I am they/them, but that's not what you understand from this
- I am not understood because I am not listened to
- I am not listened to because there's no time
- I am out of time before I've begun
- Out, patient!

I am an outpatient

I am sitting and waiting and looking around
I am waiting in anticipation
who will be next

outpatien

and wanter

I am sure I was here first

I am going to read a magazine

that will help me feel relaxed

I am hoping it's me next

I've been here long enough now

I am hearing my name now it's time for me.

I am anxious

Tam Schling

00 Kin

who will I see

what will they be like

I am walking down the corridor following the nurse

I am walking past all the closed doors

who is behind those doors

I am in a room

it's bare and scary

I can't see out of the window

I am feeling anxious

my heart is racing

I am hearing footsteps and voices

are they coming my way

I am waiting for the door to open

who will I see

I am hoping it's a woman

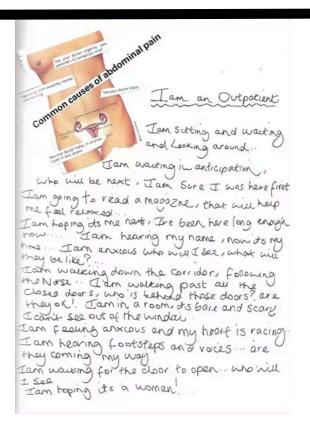
to my love, my dear NHS You have been there every day of my life

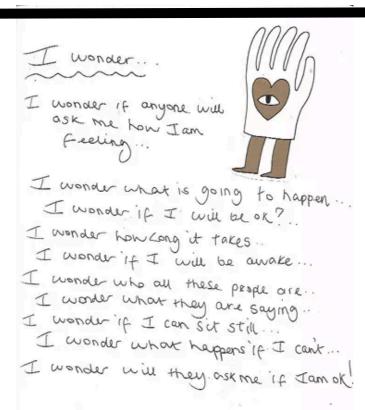
Your love is without limits of judgements

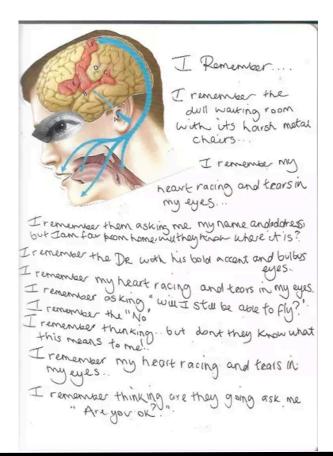
You To my Tove, my dear NHS daughter and

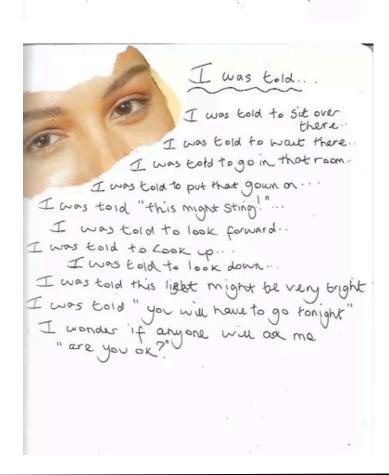
the death of my father You have been there every day of umy 11 fend partner Your love is without limits of judgements You were there for the birth of my daughter and the death of my father You have saved the lives of my daughter and partner
But Your love is like no other, and I am hopelessly dependent on you. WE don't meet up like we used to, you preter to But something has changed, you have started behaving differently We don't meet up like we used to, you prefer to catch up on the phone. I know you're busy. The amazing things you have Friends have told me the amazing things you have done but also that you have let them down too. I want to ask, "my love, are you OK?" but I am also questioning bether I can trust whether I can trust you Because without trust we are nothing. My heart is in your hands. My healt is in your hands.

scared Sometimes e out patients o I wish to be seen and heard: I wish to shout from the highest mountain that I am here I am strong, I am beautiful, I survived and will continue to do so no matter how much you try to beat me down with your rules and regulations Wish to be Sell









Fragmented

```
The shatter-scars / carve / through me
throughout
               body
Right----through----wery----being
Sliced / by \ cheese wire / into \ angular / pieces
A 3D tes
           ation
                     le
       sell
                puzz
- somewhere, if you look hard enough, you can see me -
Pieces shuffled
no one way is
              up
                                edges of each piece
Symptoms eat away at the
tangibility wanin g
- all this because they didn't stop -
           oa
Memories fl t
                   ou
                ar
                     nd
hiding behind thoughts and experiences
lurking in what f e e I s like past
then suddenly time unr a vel s
And I am everywhere
then is now is then
now is then is now
- I am not what I was -
Diagnoses roll out
                  PIECES
IN AN ATTEMPT TO MAKE SENSE OF THEM
s-t-i-t-c-h-i-n-g them with threads of I-o-g-i-c
```

- 'Experts' forecast my future in reports from notes from appointments I no longer remember -

No dictionary really defines Pain (noun): Its lightning bolts, its radiation, its felling of strength.

No thesaurus has words for: the, mist, that, hangs, between, words the expectant [voids] where information and thoughts should be.

- I don't recognise the person they're describing -

All is lost

In translation and otherwise...

Diagnoses roll out

pieces

in an attempt to make sense of them

Diagnoses roll out

PIECES

IN AN ATTEMPT TO MAKE SENSE OF THEM

Diagnoses roll out

IN AN ATTEMPT TO MAKE SENSE OF THEM

In outpatients because...

```
I am here to get some help to recover from my fractures and
I know that older bodies take time to heal and cross my fingers but
I think how lucky we are in the west with healthcare provision since
I remember mum detailing the pre-NHS cost of a GP visit so
I feel cared for with a National Health Service however
I wish I had taken more care of myself and vow to do so whilst
I can access physiotherapy although
I wonder whether the doctor will be blessed with listening skills, truly
I hope so as not all hear the anxiety, the pain or the silence moreover
I was told there will be an hour's delay before I am seen thus
I will wait patiently with others worse than me as
I want to have the most positive of outcomes because...
Ι
am
here...
```

times How many

Zo Copeland

How Many Times?

How many times

How many times

Do I need to tell you my story

How many times do I need to tell you my story

When you already have it

How many times do I need to tell you my story when you already have it

it's on your system

How many times do I need to tell you my story when you already have it - it's on your system

I've told you before

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before

It's wearing to go over things

Going round in circles

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles

Repetition

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition Repetition

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition, repetition It's disorientating

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition, repetition, It's disorientating

It makes me sick

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition, repetition. It's disorientating, it makes me sick

More questions

you aiready have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition, repetition. It's disorientating, it makes me sick, more questions

The same questions

How many times do I need to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition. It's disorientating, it makes me sick, more questions, the same questions. The answers less

to meet to tell you my story when you already have it - it's on your system. I've told you before. It's wearing to go over things, going round in circles, repetition. It's disorientating, it makes me sick, more questions, the same questions.

The answers less

and less

as I refuse to be puppeteered

and help fades away

My story a barcode

Surrender

Mapping Outpatients



The Outpatient Highway

The bus is busy, very busy! Some of the passengers have T shirts on with the number of days they have been waiting for an appointment, like charity challenges that they have set out to achieve.

I sit by the window and as the bus moves along, I can just about see the Emotional Rollercoaster. This looks busy too. I know I will be queuing to ride it later.

The bus pulls into the Shopping Mall of Appointments. This is a multi-layered building. I am overwhelmed with the shops for different medical departments and the kiosks for dates and times slots are daunting and once again so busy.

I need to breathe, so I walk to the Castle of Control; I feel safe in here and my heart slows, and my smile returns, and I feel some glimmers of hope. I climb to the top of the Grand staircase and walk out onto the top of the tallest tower; from there I can see the pathway to the headland. I picture myself standing on the cliff top, arms outstretched, breathing in and filling my lungs. My strength returns. I look towards the Sea of Hope, where brightly coloured fish, dance in the waves.

Rejuvenated, I hop back on the bus, but I know we will now need to travel through the Mountains of medication. I hear the pharmacists' voices. "Take these three times a day" 'take these in the morning" "take these before food" "take these with food" "take these after food" ... ahhhhh! I don't want to take any at all!!

The bus heads into the Hills of Sadness, where the light hardly shines. The bus driver stops the vehicle, and everyone files out. We sit on the edge of the Lake of Tears. Our tears run down our face and into the lake. They cause ripples across the water. Tears of sadness, tears of frustration, tears of anger, tears of relief, tears of beyond belief. The different tears swirl across the water in a multitude of colours, some of them lap at the edge of the Plains of Tiredness and Exhaustion.

I have visited these plains many times, and the tumbleweeds have become my friends. On the far side of the lake are the Gardens of Bittersweetness; when we walk through the gate everything looks beautiful. The trees have grown strong, and their branches reach up to the sun. The gardeners tend the flower beds, pink lilies and azure irises compete with the array of roses for the most beautiful colours and aromas. However, as you look closer, you see fruits on the trees, these fruits look delicious and inviting, and as you take one to taste, the sourness and bitterness hits your tongue, and you know its time to step out of the gardens.

Ahead of you is the Valley of Gloomy corridors. These endless corridors lead you to your outpatient appointment in the Hospital of Gloom.

I sit in the waiting room and await my turn; my heart is racing and there are tears in my eyes. The windows are high and bring a minuscule of light into the room. I stand on my tip toes to look out at the view. I can just about see the conveyor belt of doctors being churned out of the Training college. I think to myself — they entered the college with hope, passion, and enthusiasm, in their smart white coats, and now as they leave, they are dressed in dark blue scrubs, with hunched shoulders and sad faces. I want to press the reverse button and send them back and give them an injection of happiness.

Outside I can just about hear the waves crashing on shore from the Ocean of Alone, and even as I take a breath, it hangs heavy in my lungs like a dark grey rain cloud. As I look around the waiting room I feel like my fellow patients are sailors on a similar Ocean.

How does the appointment go? Well, the Doctors doesn't smile or look me in the eye. Their voice is monotone and dry. My questions and search for answers are dismissed! Times and dates are discussed but are way ahead in the future, and I think what now? I need help now, not in 300 days or was it nine months. My hearing and comprehension has already blurred.

I head out of the hospital and step onto the heart racing running track. My legs feel like lead, and I am wading through mud, but I pick up my speed. The track is busy, very busy. Children run past me, with eyes open wide. A friend runs up beside me and takes my hand, they smile and pull me along. The running gets easier, and a feeling of relief washes over me. I have survived another appointment!

In the distance I can hear everyday sounds from the Town of Anticipation. The bus peeps its horn, it's time to go home.

The bus whizzes back on the highway, as we pass the Emotional Rollercoaster the driver calls out "Anyone want to stop"? I think: not today.

I smile as we pass the Park of Kindness, I see glimmers of hope sparkling in the trees. The Positive Pastures look peaceful and serene. The Bay of Calm with its sweeping sandy beach looks inviting. The bus reaches the end of the road. "Last stop for today" says the driver. "See you again soon" I reply, but for today I am Free. The Sun is shining brightly, and the breeze is warm, and I breathe in and fill my lungs.

I walk back through the gates to the Villa of Happiness.

Outpatient Navigation

I asked about waiting times for a CT scan.

I was told...

"How long is a piece of string?"

I have learned to navigate the complexities of various services to prevent undue

anxiety

The Entourage

I walk into your consultation room, you see me; my expression, my posture, my gait. You do not see my entourage. They file in behind me, an anarchic menagerie. No space to sit down, they crowd the room, distorting the curtain, protruding awkwardly into the next cubicle.

You ask about me; rarely about them. Occasionally, but rarely. They don't get to speak. They loiter in the background. A chaotic misfit family portrait along the couch against the curtains.

Exhaustion slithers across the floor, a grey slime-cloud of a creature, picking up dirt and dust in his wake, no energy to prevent or deal with this. He slithers under the couch into the shadows.

The Driver is a stick of a man, thin from fret. He rushes everywhere, desperate to be on time — an impossible task trekking this circus troupe around. And there are never spaces since they built over carpark F and turned carpark G into staff—only. The 20 minute spot is useless if you get there early enough to get one — 20 minutes before the appointment, and the time is up before the appointment's begun. No wonder he walks in so fast, jerky and rigid. He mutters as he enters. He doesn't sit down. Restless, he paces for the duration of the appointment. Gah!

Disability hobbles in, sensitive to every movement it makes, to the light, to the sounds of the growing crowd in the room. It takes its place in the middle of the room. Noone notices.

Carer's long and slow paces pull them slowly into the cubicle. Their shoulders slope, eroded from their ongoing daily burden. They lean against the wall, then slowly slip down it to the floor, where they remain, less a puddle, more a crumpled heap.

Employee trips up over the wheely chair on her way in. She's too busy counting, plotting, planning — any and all ways to make up the hours. Adding the appointment time to the travel time. Working out which evening she can work to make it up. She perches on the edge of the couch, her spine held upright by adrenaline alone.

Queerness makes an entrance, obviously. Deliberately juxtaposed to the rest of the rabble. All eyes watch them roll in and sit down on the couch in a smart-casual pose indicative of a magazine shoot. Noone says anything, in case of awkwardness.

Ghost of Appointments Past hovers into the room, her transparent form expanding to take up space. Swirling within her mist of a body are the echoes of sound from before. 'You just need to do more activity — as much as possible.' 'You understand it very well, so you don't need me.' 'There's nothing more I can do.' 'I know it's a nightmare to park, but if you're not here, you miss your appointment.' Slowly they merge into one disjointed noise, and the soft voice of the caring physio 'how are you? This has been going on a long time. Let's be thorough...' is drowned. And the sound of someone listening — well, that can't be played.

A slither of a face appears in the crack between the curtains. The one visible eye darts about the 'room' inside, careful not to make eye contact. It disappears. Then comes back again, silently, to check, before disappearing again. Fear lives this pattern. Its sense of time is not linear.

Debt is a malleable red blob that bounces in, leaving a dent under his weight with each jump. He can't be still. He moves with entitlement and no regard for the others, not looking back even so much as to notice the trail of imprints he's left.

Redundant-Unemployed-Part-Timer is a wisp of a thing, unsure of her name. She slinks in past the others, apologising for brushing past them, apologising for them moving out of her way. She loiters in the corner, sheepish, staring at the floor.

Anger is a balloon of a creature, almost fit to burst, but not quite. He wobbles in like a space hopper with no rider, awkward and overly self-aware. He stops in the middle of the room, defiantly, ready to stare you down. From behind I can see the angles of his favourite placards poking out of his back pocket; 'fuck you all' and 'just fuck off.' I chuckle to myself.

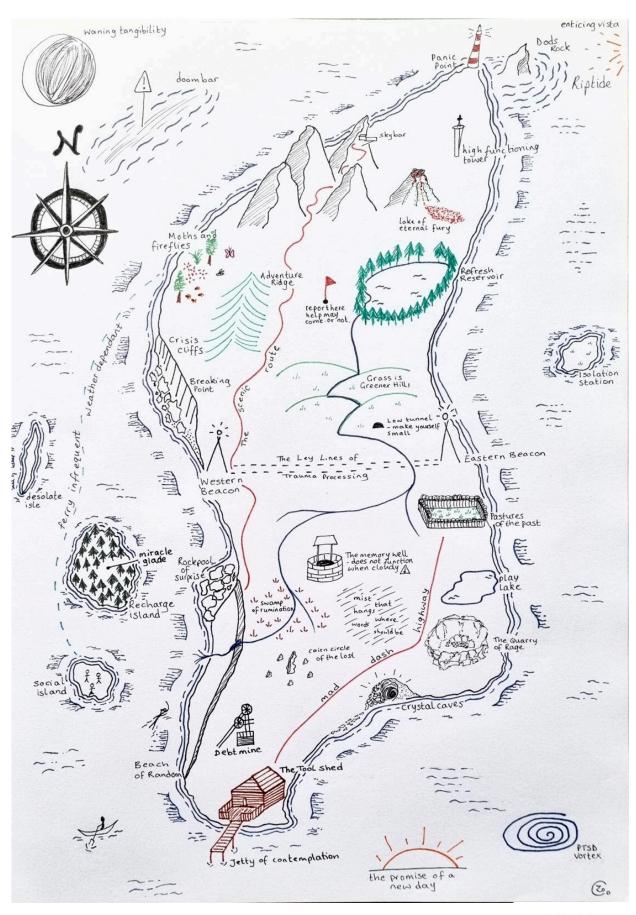
Pain whips himself into the cubicle from nowhere. His shiny outfit is so bright everyone turns away or shields their eyes. He's brought a stuffy heat into the cubicle, and the others all inch away from him as he makes his brazen way to the couch and lies down under it, next to exhaustion.

Concussion wanders in last, once the appointment has begun. It looks around, confused, like it was expecting something else to be happening. It makes a sound as if to speak, but it's unintelligible. Then it seems to give up and takes a seat on the floor next to Carer, squinting at the fluorescent tube overhead.

Case Handler rushes in late, dramatically, and uninvited. Her face is red, her eyes wide, her breathing irregular. She takes her backpack off her shoulders and pulls out a laptop to open. As she does so, she litters the floor with crumpled printed A4 pages, solving the conundrum of where my emails go. She opens the laptop to a greeting of pings and pops, then adds a percussive clacking over the top of the mechanic melody. Concussion and disability look at each other in disbelief. Anger's left eye starts to twitch.

Trauma drives in, unannounced — in that old Micra from when it all happened. It drags its curled up, fleshy body out, just outside of the curtain and scuttles up the wall and along the ceiling, taking its position on top of the light tube. The light cast over the room begins to judder — as Trauma watches down on everything that's happening — it's shaking.

Concussion shuts its eyes.



Listen to recordings of Zo Copeland's pieces from this project and hear about their map using the $\ensuremath{\mathsf{QR}}$ code.



auxilium

I am sick.

I have suffered.

I need you to hear my pain.

I need hope.

I have tried to overcome this.

I have waited for things to improve

I am vulnerable.

I am not of strong body but hopefully you can help me to improve.

I am here with hope.

I will treat you patiently and with respect whether staff, nurse or doctor.

You can listen to me.

You can examine me.

You can ask me questions.

You can promise to be in my healthcare team — an ongoing relationship.

You can treat me as if I were a member of your family. You can inform me, offer me choices all the while mindful not to do me any harm be that physical or psychological. That is the guiding principle of healthcare 'primum non nocere'.

Walk in my shoes.

primum non nocere

firstly do no harm will be my guiding star. starlight will illuminate my students, my colleagues, my patients.

I will try to do my best for you.

I will listen to your words and your silences.

I know that listening is the first step towards healing.

I will refrain from judgement and negative opinion which will cause harm.

primum non nocere.

I will employ my skills and my knowledge and offer you the best possible options.

I will not generalise on gender, age or similar.

I will treat you as the equal that you are.

I will be compassionate as I work with you.

I will be honest and direct when you ask challenging questions for which I may not have an answer.

I will help you if I can.

I will listen to your silences.

I promise to do you no harm.

Pactum:

Background to poems auxilium and primum non nocere

For the most part, outpatient clinics and appointments run reasonably well in this country considering a lack of resources, low staff morale, the impact of governmental underfunding and broken promises. Quality of care should not be dependent on where you live or what condition you may be suffering from, but it does vary considerably throughout the country and trained doctors are looking to other parts of the world for employment. The NHS is unsustainable if no changes are to be made short and long term.

We can hope for political change with a new government in power but any change will take time.

I have lost count of the number of outpatients appointments I have attended over the decades so have many experiences, mostly good but it's the bad and avoidable ones that scar the most and do avoidable harm.

All medical staff have a duty of care and all patients have a duty to behave respectfully and cooperatively.

I fully understand the fear and outrage behind notices to the public stating that it is not ok for the general public to use threatening behaviour, violence or abuse towards staff because it isn't ok at all. This is quite clear. Less clear to patients are the experiences where control over our health is masked by a powerful, mainly male, well-educated medical establishment who hopefully, have all consented to some kind of medical-ethical agreement based on the Hippocratic oath. This is not a reflection on male doctors per se but far too many patients, mainly women, still attest to sexist and ageist attitudes from doctors (see the BMA's Sexism in medicine report on their website) and (Is the NHS ageist? by Grace Gottlieb, published by the Royal College of Surgeons journal, Bulletin.) It is important to note that the BMA survey of women doctors in 2021 showed that 91% of women doctors at work in the UK have experienced sexism at work with 42% feeling unable to report it. Whilst the BMA recognises this, little has actually changed and if women doctors are being patronised by their male counterparts, where does that leave female outpatients?

Perhaps the creation of an agreement/contract placing responsibilities both on the patient and the physician and all who work in outpatients embracing the theme of equality could be the way towards a reimagining of outpatient clinics and their outcomes.

I've used the word pactum from the Latin - Latin because it is the universal language of medicine although Hippocrates, considered to be the father of medicine was Greek. The titles hark back to the past and the basics for good healthcare. The Latin auxilium is a request for help which everyone attending outpatients is aware of and hopeful of.

primum non/nil nocere from the Hippocratic and other subsequent oaths are about medical ethics. Patients and doctors have an ethical duty towards each other. We are each reflections of the other.

invitationem

This is an invitation to add, subtract, alter, rewrite your personal medical 'pactum' to serve as an agreement between practitioner and patient

In reimagining we get closer to how things could and should be in the future

