OVERVIEW FOR CLINICAL TEAMS

YourTubie Passport

A self-management tool for people living with artificial nutrition at home, both enteral tube feeding and parenteral nutrition. Built by a long-term patient, for patients.

It gives a person one place to keep their feed regime, their line and tube care, their bloods, their stock, and their emergency information, and one card to hand to a clinician who has never met them before.

What this document is for

To let a nutrition team see what the tool does, what it deliberately does not do, and what would be involved in using it more widely, either hosted independently to NHS information-governance standards, or handed over to a trust to run on its own infrastructure.

Prepared for: Home Parenteral / Enteral Nutrition team
Built and maintained by: Daz, TPN Explorer
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Why this exists

People on home artificial nutrition carry a large amount of information that no single record holds in one place: which feed, at what rate, over how many hours; which line, inserted when, changed how often; which lock, which antibiotic, which organism last time; who to ring out of hours. Most of it lives in a person's head, in a folder, or across several systems that do not talk to each other.

That works until the moment it matters most: an unplanned admission, an out-of-hours call, a locum who has not met the patient, a hospital that does not routinely see home parenteral nutrition. At that point the person who knows the regime best is the patient, and they are usually the least able to explain it.

This tool was built after exactly that experience. It began as one patient's answer to the question *"what do I wish I could have handed them?"*, and every feature in it traces back to something that was missing at the time.

> **A note to the team reading this**
>
> You already know the admissions this came out of. You were the ones who told me to go in. So this is not an account of what happened; you have that. It is an account of what I did not have with me when I got there, and what I have built since so that the next time is different.
>
> Almost everything in the pages that follow exists because of a specific gap: a question I could not answer quickly, a history nobody could see, a number I could not produce, or a phone call that had to wait until morning. Where something looks oddly specific, that is why.

What it does

The tool is organised around what a person actually needs to do, not around what is easy to store.

An emergency card that can be handed over or printed

A single screen showing nutrition type, vascular access, allergies, and the people to contact, led by a prominent catheter-related bloodstream infection warning telling a treating clinician to stop the infusion and not use the line if the patient is febrile or unwell. It prints to one page and works without a login on the person's own phone.

An SBAR handover

The person's current situation, background, assessment and recommendation, generated from what is already recorded, in the format a clinical team already uses.

Feed regime and a live feed companion

Prescribed feed, pump, rate, duration, bag size and energy content, with a running companion that tracks a feed in progress and logs what was actually delivered: including feeds that were stopped early, which is usually the clinically interesting case.

Line and tube care

Device insertion dates and change intervals with an overdue prompt, exit-site condition logging, line-lock records including causative organism, and a complications log that recognises outcomes such as being discharged to self-care at home.

Observations and trends

Weight, temperature, blood glucose, fluid balance, blood markers and mood, with plain-language help attached to each field so the person understands what they are recording and why it matters.

A food diary for people who can still manage some food

Not everyone on artificial nutrition is nil by mouth, and tolerance changes over time. This records what was eaten or drunk, how much was actually managed, and how the person was afterwards: nausea, pain, bloating, vomiting, and any change in stoma or bowel output. Calorie, protein and fluid figures are optional, so a difficult day is still one line to log. Over time it builds a picture of what is tolerated and what is not, and combines oral intake with feed intake into a genuine daily total.

Stock and ordering

Consumables tracked at the level they are actually used: individual caps, swabs and syringes rather than boxes, deducting automatically as feeds are connected and disconnected, with reorder thresholds and a generated order for the homecare provider.

Documents, care team and peer support

Clinic letters and care plans kept alongside the record, contact details for the people involved in the person's care, and a moderated space for others living with the same thing.

How this helps someone fed by tube

Where feeding is temporary

Someone tube-fed for a defined period: post-operatively, during treatment, or while gut function recovers, is usually learning an unfamiliar routine at the same time as being unwell. The value here is structure while the learning happens: a place to keep the regime, a prompt when a device change is due, a record of what was tolerated as oral intake is reintroduced, and an emergency card for the period where they are managing at home but not yet confident. When feeding stops, the record of what happened remains.

Where feeding is long-term or permanent

Someone years into home parenteral nutrition has the opposite problem: they know their regime intimately, and no system holds that knowledge in a form anyone else can read quickly. The value here is continuity and evidence: a line history that shows every lock, organism and complication in sequence; weight and bloods trended over years rather than between appointments; a tolerance record built from hundreds of small observations; and the ability to arrive at any appointment, or any hospital, with all of it in one place.

For the clinical team

The tool is deliberately not a shared clinical system, and does not attempt to be a record the service is accountable for. What it offers a team is a better-prepared patient: someone who arrives with their regime, their history and their questions already assembled, and who can hand a treating clinician a legible summary in an emergency. Anything from it that belongs in the clinical record still has to be entered there by the team, exactly as it would be from any patient-held diary.

What it deliberately is not

- **It does not give medical advice.** It calculates nothing clinical, recommends no treatment, and adjusts no regime. Every page carries a disclaimer directing the person to their nutrition team, and to 999 in an emergency.
- **It is not a medical device** as things stand, precisely because it does not interpret data or drive a clinical decision. If it were ever extended to do so: flagging results as abnormal, suggesting a rate change. That would likely change, and would need proper assessment before it went anywhere near a patient.
- **It is not a substitute for the clinical record**, and is not affiliated with, endorsed by, or connected to the NHS, any manufacturer, pharmaceutical company or homecare provider.
- **It is not monitored.** Nobody is watching the data. A person entering a worrying observation must still contact their team.

Seeing it for yourself

Rather than take any of this on trust, there is a demonstration copy of the site you can sign into and use.

> **This is not the live site**
>
> The demonstration site is a separate copy holding invented records only. The name, diagnosis, figures and contacts in it belong to nobody. Nothing you do there touches any real person's records, and no real patient data is reachable from these sign-ins. Every page of it carries a banner saying so.

WHAT	SIGN IN WITH
As a patient A populated example record: three weeks of feeds, a food diary showing a tolerance pattern, line history, stock and observations.	`demo@yourtubiepassport.uk` `ClinicDemo2026`
As an administrator The oversight view, so you can confirm for yourself that it shows account details and record counts only, never anyone's clinical content. Read only.	`review@yourtubiepassport.uk` `ClinicReview2026`

Full page, including these details:
`yourtubie-passport-dev.trymysite.co.uk/for-clinicians.php?key=nutrition-team-2026`

How information is protected

The design assumes from the outset that this is the most sensitive category of personal data there is.

- **Registration is invite-only.** There is no open sign-up. Invitations are single-use, expire after 14 days, and bind to the email address they were issued to.
- **Clinical content is never visible to an administrator.** The admin area shows account-level information and record counts only, how many entries exist, never what is in them. Passport, feed, observation, note and document content is visible only to the person it belongs to.
- **Every record is scoped to its owner** at the point it is read, changed or deleted, so one account cannot reach another's data.
- **Traffic is encrypted**, session cookies are restricted, and every state-changing action is protected against cross-site request forgery.
- **No tracking or advertising.** A single session cookie to keep the person logged in, and no third-party analytics.
- **Peer support is moderated**, with reporting, blocking and published community guidelines.

> **An honest statement of current scale**
>
> At the time of writing this is a personal project in daily use by its author, not a service with a user base, a support desk or an uptime commitment. The engineering is sound and the tool works, but nothing in this document should be read as a claim that it has been independently assured, clinically validated, or tested at scale. Any wider use would need the steps set out over the page.

If this were to be used more widely

There are two realistic routes, and they place the responsibility in very different places.

Option A: hosted independently, to NHS information-governance standards

The author continues to host and maintain the tool, and brings it up to the standard expected of anyone holding patient data. The requirements are well-defined:

REQUIREMENT	WHAT IT INVOLVES	COST
Dedicated UK hosting	Its own virtual server in a UK data centre, holding this application and nothing else, with encryption in transit and at rest, key-only administrative access, firewalling, monitoring and nightly encrypted off-site backups.	~£12-15 / month
ICO registration	Data-protection fee, payable once per organisation rather than per application.	~£40-60 / year
Data Protection Impact Assessment	Formally required for health data. Groundwork can be prepared in-house; it must then be reviewed and signed off by a qualified data-protection professional.	~£300-800 one-off
Data Security & Protection Toolkit	NHS self-assessment, renewed annually.	Free
Data processing agreement	Signed with the hosting provider.	Included
Privacy notice & retention policy	Published, plus a defined position on how long data is kept and how a person exports or deletes theirs.	Included

Indicatively: around **£700-1,200 in the first year**, and **£350-400 a year thereafter**, most of it the server and the ICO fee. Development and maintenance are not charged.

> **The limit of what can be self-certified**
>
> The technical work: hardening, encryption, backups, isolation, access control: can be done in-house, and the DPIA and toolkit groundwork can be drafted in-house. **Compliance itself cannot be self-certified.** A qualified data-protection professional needs to review the DPIA and confirm the position before any patient data beyond the author's own is held. That review is the one step that cannot be substituted.
>
> It is also worth stating plainly that if the tool were opened to other patients, UK GDPR duties would apply immediately, independently of anything the NHS asks for.

Option B, handed over to the trust

The alternative is to give the tool to the service outright: the source code, the database structure, the deployment instructions and the documentation, for the trust to host on its own infrastructure.

This is the cleaner option from a governance point of view, and in most cases the more realistic one. The application then sits inside an existing information-governance framework, under an existing data protection officer, on

infrastructure already assured, with an existing route for incidents and subject-access requests. None of that has to be rebuilt from nothing, and the liability sits where the accountability already sits.

The practical requirements are modest: it is a standard PHP and MySQL application with no unusual dependencies, and will run on ordinary web hosting. It can be handed over with its schema, deployment notes and full history. Support during a handover, and any adjustments the service wanted first, would be provided without charge.

A suggested next step

Rather than deciding between the two now, the most useful next step would be for the team to look at the tool as it stands, particularly the emergency card, the line history and the food diary, and say whether the information it captures is the information the service would actually want a patient to bring. That answer shapes everything else, and costs nothing to establish.
