DHCF

THE DHCF MANIFESTO

Citizens Own Their Health

but not yet their health data.

Stuart Mackintosh · Bert Verdonck · Alexander Inchbald · UNITED · September 2026 · V7 draft

HOW TO READ THIS

This is DHCF's manifesto: 95 short, declarative theses in the lineage of Luther's 95 and the Cluetrain Manifesto's 95, translated into the language health has been waiting to hear. Each thesis stands alone, sharp enough to carry a single article and a single post. Together they build a worldview.

The title is a statement of fact, not an aspiration. Citizens do own their health. The argument is not about whether people own their own health. It is about the data, which they do not yet own, and cannot yet reach.

Citizens own their health, but not yet their health data. When they do, the record follows the citizen, not the institution. Health data is everything a life gives off, from every source and every tradition; the architecture is built so anyone can inspect it, use it and improve it, and no one can lock it away; trust is built structurally, not declared; every citizen, without exception, is owed the same ownership; and each working example makes the next one possible. The last thesis invites the reader to sign their name.

WHY A MANIFESTO, WHY NOW

In 1517, Luther nailed 95 theses to a church door in Wittenberg[1] at the exact moment the printing press could carry them further than any door ever could. In 1999, four technologists wrote 95 theses about markets and conversations at the exact moment the web could prove them right within a decade. Both moments shared the same shape: a system that had drifted from its promise, a technology just mature enough to make the gap impossible to ignore, and a document short enough to spread on its own.

Health is at that same moment now. The technology to give citizens back their own data – interoperable, open source, and now mandated in European law through the European Health Data Space – already exists, and the law sets the date: citizen access to the first categories of data from 2029. The right exists; the infrastructure to exercise it does not. What has also been missing is the statement that names what the technology makes possible. That statement is this manifesto.

EVIDENCE

Every thesis is a claim, and every claim carries a source behind it, and the sources are listed later on in the document.

PART ONE

Theses 1–15

The record isn't available.

The gap the title leaves open, the business model that keeps it there, and what it costs in a ward.

1 Citizens own their health. They do not yet own their health data.[2]

2 The quiet trade in health data is a business model, working exactly as designed.[3]

3 Every closed system defends itself the same way: by claiming openness would be dangerous.[4]

4 The first act of health justice is naming who currently profits from injustice.[5]

5 A hospital keeps the file. Industry claims the raw data. A platform learns the pattern.[6]

6 Every corporation is designed to return a profit. The failure is systemic, not personal, and the system is what we change.

7 A healthcare system built to profit from data cannot also be trusted to provide care.

8 Patient consent is easy to give, hard to limit, and even harder to take back.[7]

9 The citizen who generates the data becomes the last to benefit from it.

10 A patient's condition, told to a doctor in confidence, should not become a corporation's asset.

11 Locked data slows cures, delays care, and costs lives.[8]

12 Indifference protects the system. Scrutiny changes it.

13 The right data in the right place at the right time prevents thousands of avoidable harms.[9]

14 Care happens in the ward, the home, the surgery and the ambulance. Data that reaches all four prevents medication errors, missed histories, and deterioration nobody caught in time.[10]

15 Health data that was taken in secret must be handed back in daylight.

PART TWO

Theses 16–29

Health data is memory, not merchandise.

What a record actually is, who should hold it, and why holding it early matters more than holding it late.

16 Ownership is a relationship, and right now that relationship is broken.

17 The cure begins with a single reversal: the record follows the person, not the institution.

18 Every record is an experience someone lived through – a fever, a fracture, a fear, a recovery.

19 Health data is the memory of a life still being lived – and memory belongs to the one who lived it.

20 A citizen's health data is a reflection of the body it came from – and deserves the same respect.

21 Health data is bigger than any hospital file. It is your sleep, your steps, your heart rate. Know where it is.[11]

22 Health is whole, and so is your record. It should open to whoever you trust to help – a physician, an osteopath, a nutritionist, an Ayurveda practitioner, a family member, a friend.

23 A system that asks a patient to retell their story at every door has already failed them.[12]

24 Every citizen holds the licence on their own data. They should know who its custodians are, and get to choose them.

25 The health system meets most people only once they are sick enough to qualify. A record you own lets you look after your health long before that. That is prevention, and it is where the system invests least.[13]

26 When the citizen decides who sees their data, trust becomes possible across the whole system.

27 Any institution can call itself patient-centred. Only what the patient reports settles it.

28 Efficiency is not the opposite of dignity. Time saved on the record is time returned to the patient.

29 A citizen who owns their record owns their health story.

PART THREE

Theses 30–42

Open is not a threat. It is the architecture.

Open means one thing here: anyone may inspect it, use it and improve it, and no one may lock it away. From what a commons is to how it is governed.

30 A commons is shared infrastructure everyone can use and no one can enclose. A record held inside one company can never follow you. A record held in a commons can.[14]

31 In a commons, everyone holds the keys together: no gate, no gatekeeper, no single hand on the lock.

32 Open source is a form of accountability: anyone can inspect what shapes their care.

33 What is proprietary can be hidden. What is published can be checked.

34 No single company should hold the master key to a nation's health.

35 Interoperability is a citizen's right to be understood wherever they are treated.[15]

36 A record should say how sure it is. A reading taken once, years ago, is not the same as one taken this morning, and the record should show the difference.

37 Systems that admit what they do not know earn more trust than systems that claim what they cannot prove.

38 Health institutions should hold data as custodians, not owners: a duty of care, not a claim of possession.

39 What is built in public cannot be quietly enclosed later.

40 Standards travel further than silos ever will.

41 A shared architecture lets every hospital, every clinic, every citizen speak the same language without surrendering to the same master.

42 Governance of a commons belongs to everyone who depends on it, not only to whoever built it first.[16]

PART FOUR

Theses 43–56

Trust is built, not declared.

From transparency as a daily practice to trust that survives a change of management.

43 An institution earns trust by showing how it works.

44 Transparency is an operating principle, built into how a system runs.

45 Consent, done properly, is an ongoing conversation between citizen and system.

46 A citizen should always be able to see who has looked at their record, and why.

47 Trust infrastructure means the default is visibility, not the exception.

48 When an institution is wrong, admitting it builds more trust than pretending it wasn't.

49 A system that shows its vulnerability makes honesty its default – and people trust a default they can see.

50 Shared governance between citizens, clinicians, and institutions is slower to build and impossible to fake.

51 The European Health Data Space is a regulation and a central platform. That is a beginning, not an achievement.[17]

52 A regulation can unlock a door. Only a commons keeps it from being locked again.

53 In an emergency, the record that can save a life should reach the bedside faster than the ambulance.[18]

54 Every citizen who understands their rights over their own data becomes a guardian of everyone else's.

55 Trust, once structurally embedded, no longer depends on any single good actor remaining good.

56 Health infrastructure should be something citizens can rely on, not something they hope will hold when they need it most.

PART FIVE

Theses 57–70

Every citizen. No exceptions.

From equity as a design requirement to prevention as the part of care most people never reach.

57 Health for all was never meant to stop at the border of income, geography, or system.

58 A citizen in Luxembourg and a citizen in Poland deserve the same ownership over the same kind of record.[19]

59 Health equity is not a value statement. It is a design requirement.

60 A system that only works for the insured, the urban, or the connected has not yet built the commons it claims to.

61 Prevention, cure, care, rehabilitation, and prevention again. One loop, and one record, or it breaks at every handover.

62 When a system is built for the most excluded first, it has the potential to be the most inclusive for all.

63 Fragmented data harms most where it is least visible – in mental health, the patient history that's most valuable in a crisis is the least likely to travel with the patient.[20]

64 Ownership of your health record is a birthright, never something you must qualify for.

65 A refugee, a retiree, and a newborn generate the same kind of record – and hold the same right to it.

66 Health data that travels with dignity restores dignity to the health system itself.

67 The founding constitution of the World Health Organization names the highest attainable standard of health a fundamental right of every human being. A right, never a transaction.[21]

68 A commons reduces inequality by design – equity is the architecture, not a side effect.

69 Inclusion is not a claim an institution makes about itself. It is measured by who is missing from the record.

70 Every citizen owning their health data is the foundation everything else stands on.

PART SIX

Theses 71–85

Each open system makes the next one possible.

How a movement spreads by proof rather than persuasion, and why patient capital belongs at the start of it.

71 Institutions do not build software. People do – and it takes a community of people to sustain it.[22]

72 Every shared standard that health adopts makes the next one easier to adopt. That is how the internet was built, one agreement at a time.[23]

73 Health has not yet had its open-source moment. It is about to.[24]

74 Every hospital that publishes its data architecture makes it easier for the next one to justify doing the same.

75 A network effect is not a marketing term here. It is the actual mechanism of change.

76 Software built this way has already generated trillions in shared value. Health is the largest commons still waiting to be unlocked.[25]

77 Philanthropic capital buys the runway for a system to become unstoppable on its own.

78 Government funding proves a mission is credible. Philanthropic capital proves a movement is ready to scale.

79 What works in one country becomes the reference case for every country that follows.

80 A citizen-owned health commons in one place is an invitation everywhere else.

81 When a citizen shares their data for research, the recognition returns to them – value flowing back to its source, not away from it.

82 A commons is a standard for markets to adopt, not a product for them to buy.

83 The organisations that join early define what advantage means from now on.

84 Every partner who opens their data is a co-author of the next chapter, not a donor to someone else's.

85 A commons spreads by proof, one working example at a time.

PART SEVEN

Theses 86–95

Begin today.

From the one thing a reader can do this week to the signature at the end.

86 Begin where you are. A single record, opened honestly, is a beginning.

87 If you are a clinician, tell your patient what you can see about them and what you cannot.

88 If you are an institution, name what you currently hold and ask, honestly, who it truly belongs to.

89 If you are a technologist, build the standard that makes the next system's job easier, not harder.

90 If you are a funder, back the infrastructure, not the appearance of progress.

91 If you are a citizen, ask the question no one has been asking you to ask: where is my data, and who is using it?

92 Every citizen who asks where their data is, and who profits from it, shifts what institutions believe they can do.

93 Someone has to hold this space until every citizen owns their own health.

94 Health data returned to its rightful owner is the first act. Health returned to its rightful owner is the whole point.

95 Sign your name to the health you intend to own.

PROVENANCE

What changed, and why

CHANGE LOG V7

A commons that asks institutions to show their working has to show its own. This is v6's working.

Sources added Every thesis that asserts a fact now carries its evidence at the point of claim. Theses 1, 3, 4 and 5 gained the citations they had been asserting without: the European Patients' Forum survey on who can actually reach their own record, the leaked Halloween documents on how closed systems argue against openness, and the Information Commissioner's ruling on the Royal Free and DeepMind transfer.

Corrected on the evidence Thesis 67 cited SDG 3 for a right that SDG 3 does not establish; it now cites the WHO Constitution, which does. Thesis 63 was rewritten around what the information-continuity research shows. Thesis 25 now says prevention is where the system invests least, which the spending figures establish, rather than where most of the value is, which they do not. Thesis 79 lost a count it could not justify.

Rewritten, then restored Thesis 11 was narrowed to delay and risk, and is restored to its original form now the mortality evidence is attached. Thesis 24 keeps the licence, which says what is meant. Thesis 71 was recast around institutions and community, and its source changed to match: the kernel figures speak to institutions, where the earlier citation spoke only to individuals.

Checked The medication-discrepancy citation was verified against the published paper and its title, authors and findings corrected. The European Health Data Space application calendar was read against Article 105 rather than summarised from secondary reporting.

References

[1]Luther, M. (1517). 'Disputatio pro declaratione virtutis indulgentiarum', dated 31 October 1517 and in print across Germany within weeks https://www.britannica.com/topic/Ninety-five-Theses

[2]Only a third of European patients surveyed had access to their own electronic health record; almost half had none, and where access was refused the most common reason given was simply that it is not granted to patients. Asked whether they wanted it, 85.7% said yes – European Patients' Forum (2020). 'Electronic Healthcare Records Survey' https://www.eu-patient.eu/globalassets/policy/ehr-survey-2020_summary_final.pdf. Across the EU-27, medical images are available to citizens in 26% of cases and implant and device data in 52% – European Commission (2024). 'Digital Decade eHealth Indicator Study' https://digital-strategy.ec.europa.eu/en/library/digital-decade-2024-ehealth-indicator-study.

[3]Of 24 top-rated medicines-related apps analysed, 79% shared user data; 55 entities owned by 46 parent companies received it, and those third parties advertised the ability to pass it on to 216 further parties – Grundy, Q. et al. (2019). 'Data sharing practices of medicines related apps and the mobile ecosystem', BMJ 364:l920 https://www.bmj.com/content/364/bmj.l920. At the wholesale end, IQVIA reports access to more than 1.2 billion anonymised patient records across more than 60 countries https://www.iqvia.com/insights/the-iqvia-institute/available-iqvia-data.

[4]Microsoft's internal 1998 analysis of open source, leaked as the Halloween documents, conceded privately that open source was long-term credible and that commercial quality had been exceeded by open projects, whilst setting out a public strategy of fear, uncertainty and doubt and of de-commoditising open protocols http://www.catb.org/~esr/halloween/halloween1.html. The company's public position at the time was the opposite of its internal one https://en.wikipedia.org/wiki/Halloween_documents.

[5]The beneficiaries are nameable and listed. IQVIA, formed from the merger of IMS Health and Quintiles, holds more than 1.2 billion patient records across more than 60 countries and sells access to them to the pharmaceutical industry https://www.iqvia.com/solutions/commercialization/data-and-information-management. Health apps pass user data to a median of three separate recipients, who advertise onward sharing to hundreds more – Grundy, Q. et al. (2019), BMJ 364:l920 https://www.bmj.com/content/364/bmj.l920.

[6]In 2017 the Information Commissioner's Office ruled that the Royal Free London NHS Foundation Trust had unlawfully passed identifiable records covering 1.6 million patients to Google DeepMind to develop an alerting application, that the volume was excessive, and that patients would not reasonably have expected their data to reach a third party this way https://ico.org.uk/action-weve-taken/enforcement/royal-free-london-nhs-foundation-trust/. The hospital kept the file; a platform received the pattern.

[7]1.6 million Royal Free patients were held to have given implied consent to a transfer they were never told about, could not limit, and learned of only when the Information Commissioner ruled it unlawful – Information Commissioner's Office (2017) https://ico.org.uk/action-weve-taken/enforcement/royal-free-london-nhs-foundation-trust/. Health apps that share user data with third parties largely fail to disclose it, leaving nothing for a user to withdraw from – Grundy, Q. et al. (2019), BMJ 364:l920 https://www.bmj.com/content/364/bmj.l920.

[8]Up to 48,000 people a year die of sepsis in the UK alone, against 245,000 cases; patients who present early are around half as likely to die as those who present late – UK Sepsis Trust, 'References and Sources'

https://sepsistrust.org/about-sepsis/references-sources/. The National Confidential Enquiry into Patient Outcome and Death found sepsis to be a major cause of avoidable mortality, with outcomes affected by delays in antimicrobial and source control https://link.springer.com/article/10.1007/s00134-020-06001-w. Delay is the mechanism, and it is routine: 32% of UK outpatients affected by missing clinical information experienced a delay or disruption to their care, and 20% carried a risk of harm – 'Missing Clinical Information in NHS hospital outpatient clinics', BMC Health Services Research (2011) 11:114 https://pmc.ncbi.nlm.nih.gov/articles/PMC3118108/.

[9] Extrapolating the UK outpatient study to all NHS attendances gives around 2 million consultations a year carrying a risk of harm from missing information https://pmc.ncbi.nlm.nih.gov/articles/PMC3118108/table/T4.

[10] Of 449 unintended medication discrepancies found in 215 hospitalised patients, 31.6% were of severe potential clinical relevance; 45.9% arose at admission, and half of those were still present in the discharge letter – Hermann, C. et al. (2026). 'Unintended medication discrepancies across key stages of the in-hospital medication process: a retrospective real-world study in hospitalized patients', BMC Health Services Research 26(1) https://link.springer.com/article/10.1186/s12913-026-14581-4. On deterioration, the Royal Free deployed an alerting application precisely because acute kidney injury was going unnoticed in patients already in its care, and projected that catching it would return over half a million clinical hours a year https://www.nationalhealthexecutive.com/Research-and-Technology/patient-data-transfer-to-google-deepmind-by-trust-deemed-unlawful-by-ico. Baseline discrepancy rates: Cornish, P.L. et al. (2005), Archives of Internal Medicine 165(4), 424–429 https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/486421.

[11] 72% of respondents to the European Commission's eHealth Week poll used apps or wearables to measure their physical activity, and 56% were concerned about the security and privacy of what those devices captured https://digital-strategy.ec.europa.eu/en/library/ehealth-week-2017-52-eu-citizens-want-online-access-their-health-records. That data leaves the device: 79% of medicines-related apps analysed shared user data onward – Grundy, Q. et al. (2019), BMJ 364:l920 https://www.bmj.com/content/364/bmj.l920.

[12] In over half of UK outpatient consultations with missing information the clinician relied on the patient to supply it, and proceeded to a decision without it in 20% of cases – BMC Health Services Research (2011) 11:114 https://pmc.ncbi.nlm.nih.gov/articles/PMC3118108/.

[13] EU countries spent €90.4 billion on preventive healthcare in 2022, 5.5% of current healthcare expenditure and 0.57% of GDP – Eurostat, 'Preventive health care expenditure statistics' https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Preventive_health_care_expenditure_statistics; across OECD countries the long-run figure is around 3% https://www.oecd.org/en/publications/health-at-a-glance-2025_8f9e3f98-en/full-report/health-expenditure-on-prevention-and-primary-healthcare_e65bf24a.html.

[14] Definitional, following the institutional economics of common-pool resources: Ostrom, E. (1990). Governing the Commons: The Evolution of Institutions for Collective Action, Cambridge University Press https://doi.org/10.1017/CBO9780511807763.

[15] Now a right in EU law rather than a metaphor: Regulation (EU) 2025/327, Chapter II and the MyHealth@EU infrastructure https://eur-lex.europa.eu/eli/reg/2025/327/oj.

[16] Ostrom, E. (1990). Governing the Commons, Cambridge University Press https://doi.org/10.1017/CBO9780511807763, design principle 3, collective-choice arrangements: most individuals affected by the operational rules can participate in modifying them.

[17] Regulation (EU) 2025/327 https://eur-lex.europa.eu/eli/reg/2025/327/oj establishes the legal framework and mandates the MyHealth@EU central interoperability platform. Substantive obligations apply from 2027, 2029, 2031 and 2035 under Article 105.

[18] This is what the European Health Data Space is built to deliver: patient summaries are in the first group of priority data categories to be exchangeable across every member state, through the MyHealth@EU infrastructure – Regulation (EU) 2025/327 https://eur-lex.europa.eu/eli/reg/2025/327/oj.

[19] A regulation is directly applicable in every member state without transposition, so the rights under Regulation (EU) 2025/327 are uniform by construction https://eur-lex.europa.eu/eli/reg/2025/327/oj. What differs is the national infrastructure available to exercise them.

[20] Mental health care professionals piece together a service user's history from multiple sources and curate what they pass on, and the absence of a shared information context across care settings acts as a barrier to information continuity – 'Bridging the gap: How information sharing practices across health, mental health and social care services shape information continuity', Journal of Information Science (2025) https://www.sciencedirect.com/science/article/pii/S2949856225000704. Patients with mental health conditions also experience more fragmented care for their physical conditions – 'Association Between Mental Health Conditions and Care Fragmentation', Innovation in Aging (2020) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7740954/.

[21] Constitution of the World Health Organization, adopted 22 July 1946, preamble https://www.who.int/about/governance/constitution. Within the EU, Article 35 of the Charter of Fundamental Rights establishes the right of access to preventive healthcare https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT.

[22] Since detailed tracking began, some 15,600 individual developers drawn from more than 1,400 different companies have contributed to the Linux kernel, with around a third of contributors in any given cycle contributing for the first time – The Linux Foundation (2017). 'Linux Kernel Development Report' https://www.linuxfoundation.org/press/press-release/linux-foundation-releases-annual-kernel-development-report. No single institution among them sustains it.

[23]The internet's standards were built through an open, publicly archived request-for-comment process with no central authority and no conformance certification: Internet Engineering Task Force, RFC series https://www.rfc-editor.org/; working method described in RFC 3935, 'A Mission Statement for the IETF' https://www.rfc-editor.org/rfc/rfc3935.

[24]The preconditions are now set in law and in policy: the European Health Data Space mandates interoperable records across the Union https://eur-lex.europa.eu/eli/reg/2025/327/oj, and the Digital Decade Policy Programme commits the EU to 100% of citizens having access to their electronic health records by 2030, from an EU-27 maturity score of 83% at the end of 2024 https://op.europa.eu/en/publication-detail/-/publication/bb5838fe-4742-11f0-85ba-01aa75ed71a1/language-en.

[25]Demand-side value of open source software to the global economy estimated at $8.8 trillion, against a supply-side replacement cost of $4.15 billion – Hoffmann, M., Nagle, F. and Zhou, Y. (2024). 'The Value of Open Source Software', Harvard Business School Working Paper 24-038 https://www.hbs.edu/faculty/Pages/item.aspx?num=65230. The same study finds firms would need to spend 3.5 times more on software than they do today if open source did not exist.