Letter of 20 December 2018 from the Minister for Medical Care and Sport, also on behalf of the Minister of Health, Welfare and Sport and the State Secretary for Health, Welfare and Sport, on electronic data exchange in the healthcare sector

Prompted in part by media reports on failing IT systems in healthcare, the House has urged me on several occasions and in several motions (the De Vries *et al*. motion,[1] the Ellemeet motion[2] and the Raemakers *et al*. motion[3]) to take more control of the issue of electronic data exchange between healthcare providers. This letter outlines my response and my views on this matter. Appendix 1 contains my response to the request made in the parliamentary committee meeting on administrative burden and electronic data exchange on 30 May 2018 to explain a number of specific issues associated with electronic data exchange.

1. Faster and mandatory

Good, timely exchange of information between care providers and with patients is vital to the quality of care. Because of inadequate electronic data exchange in the healthcare sector, avoidable mistakes are made, patients have to recite their case history over and over again, care providers repeatedly have to enter the same data, taking up patients' time, and tests and examinations are unnecessarily repeated. The publication that asserted IT systems in healthcare were failing[4] cited examples of things that often or almost go wrong, and led the House to raise a number of questions.[5] For example, patients are sometimes prescribed medication that is incompatible with medicines they are already using. Dangerous situations can also arise when allergy information is not automatically transferred from one care provider's system to another's. This must change, and soon. The obstacles to electronic data exchange must be tackled in the interests of patients, who are entitled to good-quality care – for which good information provision and data exchange are vital. I intend to achieve a completely electronic system for healthcare data exchange in the very near future, so that patients too will be able to access and manage all their own data. Digital must become the new normal for data exchange both within and between care institutions. Over the past few years it has become clear that digitalisation does not always happen automatically, and it is certainly not happening quickly enough, despite the fact that the time is ripe for such a development.

I will therefore take concrete steps towards making electronic data exchange in accordance with the appropriate information standards a statutory obligation. I will also ensure that all parties fulfil their role and achieve results.

I am convinced that we – parliament, the Ministry of Health, Welfare and Sport, the healthcare sector and suppliers – have a joint responsibility in this.

2. The challenge

Digitalisation of data exchange is a major challenge. The healthcare sector is large and diverse, encompassing GPs, hospitals, long-term care institutions, district nursing organisations and much, much more. The different professional groups all have their own language and this must be harmonised in a whole range of data exchanges. This will require considerable effort. There are also many different technical standards (those applying to images are for example different from those applying to documents) and some regions do not yet have their own infrastructure for electronic exchange. In short, there are failings in language and technology. Finally, there are also failings in the approach to digitalisation. In 2011 a motion submitted to the Senate by Ing Yu Tan[6] called for the government to terminate its involvement in every form – policy-related, financial and organisational – with the national electronic data processing infrastructure. Since then, the government's digitalisation approach has consisted largely of offering encouragement to parties in

[1] House of Representatives, 2017–2018 session, 29 515, no. 432.
[2] House of Representatives, 2017–2018 session, 29 515, no. 427.
[3] House of Representatives, 2017-2018 session, 29515, no. 46.
[4] https://nos.nl/artikel/2250725-haperende-ict-in-de-zorg-verkeerde-medicatie-foute-beslissingen.html.
[5] https://www.tweedekamer.nl/kamerstukken/brieven_regering/detail?id=2018Z16185&did=2018D48317.
[6] Motion by Labour Party senator Tan *et al*. on terminating the development of the National Health Data Switchboard (Senate 31 466, X).

the field and has thus, in my view, been too noncommittal. More control by the government will mean departing from this line (see also appendix 2).

3. More control through a statutory obligation

1. Introduce obligation for each care process
   Since healthcare is so diverse and the challenge so difficult, I want to introduce the statutory obligation in concrete steps. I want to see information being digitalised one care process at a time, based on clear, mandatory agreements concerning language – i.e. everyone should speak a common language – and technology. For example, I expect that information at all stages of the medication process (prescribing, issuing, administering and using medication) can be recorded digitally in the foreseeable future, based on uniform information standards (agreements concerning language and technology). This will directly benefit patients, and care providers too.

2. Coherence thanks to mandatory use of standard components for language and technology
   Digitalising information in care processes will not be enough. There must also be better digital links between them to enable data exchange. I will therefore lay down mandatory 'standard components' to ensure that the same nomenclature is used for important concepts (such as fluid balance, blood pressure and lab results) and that technical standards are also reused where possible. As a result we will not have to start from scratch each time another care process is digitalised. I therefore expect that each subsequent step in the digitalisation operation will be completed more quickly.

3. Roadmap and programme
   I invite all parties concerned to work with me to develop a roadmap within three months, identifying care processes that have priority in digitalisation and setting out the associated standards (which will be made mandatory). The digitalisation of a care process means that care providers involved in that process will exchange data electronically. To ensure that we get off to a flying start with this, Nictiz (the Netherlands' centre of expertise on e-health) has, at my request, proposed the following priority processes:
   - ambulance handover
   - services by GP locums
   - triage referrals
   - acute obstetric emergencies
   - nursing handover
   - hospital handover
   - medication
   - image exchange
   - referrals
   - youth healthcare
   - integrated care for chronic conditions.

   I will share the final version of the roadmap with the House in April. I am counting on the continued commitment of parties in the field, in anticipation of measures becoming mandatory by law.

   I will also set up a programme to manage the implementation of the roadmap, about which I will inform the House in detail before summer 2019. The Information Consultative Committee will manage the implementation of the roadmap in all sectors on the basis of ambitious but feasible deadlines.

4. More control of current instruments

Besides introducing the statutory obligation, I will continue my existing efforts (see appendix 3), and aim for a more focused deployment of the existing instruments at my disposal, to tackle obstacles relating to language and technology (see appendix 4).

Greater focus on uniformity of language

Priority care processes in the Healthcare Institute's multiannual agenda

Field standards are the way to ensure uniformity of language for data recording and handover. These must be available for the prioritised healthcare processes that are to be digitalised over the coming years, and must include rules on collaboration, handover and data exchange. The priority care processes will therefore have a prominent place in the Healthcare Institute's multiannual agenda. At the moment, field standards already exist for emergency care and for the medication process. Where these standards are in the form of best-practice guidelines,[7] they can be submitted to the Healthcare Institute to be entered in the *Register*, an online database of best-practice guidelines and instruments. Where field standards are not presented by the sector, the Healthcare Institute has the legal power to ensure that they are developed, for those processes where this is possible.

More consistent data rules

I will also take steps to ensure that digital processes are consistent, based on agreements concerning use of a common language by the entire healthcare sector.[8] The Basic Dataset for Healthcare (BGZ) could for example be used in all care processes.[9] The Healthcare Institute will publish generic agreements on reuse in all field standards as soon as possible.[10] Until such time, the Information Consultative Committee will do so.

Common nomenclature

A common language depends on a common nomenclature. In pregnancy and maternity care steps are already being taken towards a common language. In their report on uniformity of language ('Eenheid van Taal'), the National Institute for Public Health and the Environment (RIVM) and Nictiz recommended that international standards be used wherever possible in order to achieve consistency.[11] This is a major challenge. To support the field, I will stimulate that Dutch translations be made available of the international standards recommended by the RIVM and Nictiz.

IT suppliers must incorporate agreements

IT suppliers must incorporate agreements on language into their IT systems for the healthcare sector. I will contact standardisation institute NEN to discuss the scope for developing standards for technical uniformity that would be in line with agreements on a common language. My goal is for these standards to become part of care providers' quality assurance system, and to be adopted as hard criteria in the procurement of healthcare IT systems. I will also consult with accreditation organisations that audit the quality of care providers on whether data exchange can be included in their audits.

Greater focus on uniformity of technology

Setting requirements together

By joining forces and setting requirements collaboratively, care providers and their umbrella organisations can have more influence with technology suppliers. I will encourage such collaboration, which already takes place between hospitals and GPs. If neither a care organisation

[7] Quality standards are publicly accessible documents that describe best practice in relation to a particular health-related topic. Quality standards include guidelines and care standards. The Quality Standards and Measuring Instruments Assessment Framework includes criteria that quality standards must meet, focusing on how these best practices are developed and worded.

[8] 'The quality standard should be consistent with other standards listed in the Register, or any inconsistencies be highlighted.'

[9] This dataset contains the patient data that is in any case vital for the continuity of care, irrespective of specialism, disease or care professional. The BGZ is already being developed within existing funded programmes such as Registration at Source.

[10] A bill is currently before the House which includes a provision that would allow for the Healthcare Institute to perform tasks other than its statutory tasks, provided this has been approved by the Minister for Medical Care and Sport.

[11] This includes SNOMED CT, LOINC and Identification of Medicinal Products (IDMP). IDMP is a series of five ISO standards developed in response to the global demand for internationally harmonised specifications for medicines. The registration of medicines in Europe is based on IDMP.

nor its umbrella organisation is able to reach agreement with a supplier, the Secretary-General of the Ministry of Health, Welfare and Sport will hold an escalation meeting with umbrella organisations, service providers and the care providers concerned. I will also chair such talks from this autumn onwards if necessary.

Making systems open and accessible
All the systems used within institutions must be digitally linked in the future so that, provided a patient has given consent, all their data can be accessed by the attendant care professionals. This means that I expect all internal patient data systems to contain open, accessible and exchangeable data. I will contact NEN to discuss the possibility of developing standards for this, on the basis of the roadmap.[12]

Linking up regional data exchanges
I want the healthcare sector to have access in the near future to a nationwide network of interconnected infrastructures based on the technical interfaces adopted by the Information Consultative Committee. It should be possible to achieve this on the basis of existing arrangements and budgets. Several regions – such as the north of the country (Gerrit), Twente and the Achterhoek (IZIT) and Rijnmond (RijnmondNet) – already have a flourishing regional infrastructure, based on international standards. But there are also blank areas on the map. It is up to the managers of care institutions to work together to create an exchange infrastructure. They will have to do so if they are to comply with the future statutory obligation to digitalise priority data exchange.

National services
Rules and facilities are needed for data exchange at national level. Some things are already in place (like the infrastructure for UZI cards that healthcare professionals can use to identify themselves electronically). Others will need to be developed, such as rules on digital addresses for healthcare professionals and scope for searching such addresses. Some services, such as links between regional networks of care providers, will probably be put in place by the sector while others will depend on government. For instance, the National Register of Care Providers set up by the Ministry of Health, Welfare and Sport could perhaps provide access to the electronic addresses of care professionals and providers.

Information security
If we are to speed up the introduction of electronic data exchange it is vital to have a high level of confidence in information security. Care providers already have to comply with specific information security standards. I will ascertain whether these standards need to be tightened up in view of broader digitalisation. With ministry support the sector has set up Z-CERT,[13] which has specific knowledge of medical technology and of hardware and software used in healthcare, and which assists care providers in dealing with an incident. Z-CERT also offers services aimed at enhancing the sector's cyber resilience. I believe all healthcare institutions should be affiliated to Z-CERT or a similar organisation. I will therefore reassess public involvement in Z-CERT in 2019, and establish how we can bring in more participants from more sectors more quickly.

Greater focus on a directive approach
In anticipation of a statutory obligation, I will tighten my control over the current approach based on commitment devices. I will engage in talks with parties when they are unable to resolve matters in the Information Consultative Committee, or with umbrella organisations that are unable to come to arrangements with their sectoral suppliers.

Accelerating commitment devices
Adoption of a commitment device can be accelerated. If members of the Information Consultative Committee cannot for example reach agreement on a matter, I will hold escalation meetings with the managers of the umbrella organisations concerned.

[12] For instance, through open APIs – application programming interfaces. An API describes a set of rules that allows a computer program to communicate with another program or component.
[13] https://www.z-cert.nl/.

Aiming for coherence and progress

Jointly with the sector I will strive to achieve greater coherence and progress. For example, funding of any new programmes could be tied to conformity with all agreements concerning data exchange made in the Information Consultative Committee and set out in field standards. Funding recipients could also be required to report on coherence with other programmes. As recommended by KPMG,[14] I will work with the members of the Information Consultative Committee to produce a comprehensive overview by summer 2019 of the main programmes over which the Information Consultative Committee and the ministry should exercise more control.

4 Funding

The government has made more than €400 million available for programmes to speed up information exchange in various sectors. Electronic data exchange has a prominent place in the framework agreements with the healthcare sector, in incentive programmes and also in the report of the Taskforce that explored the concept of 'The Right Care, in the Right Place'. Besides through existing incentive programmes, digitalisation of data exchange will be achieved within care institutions' normal operations, which will be paid according to the current rates. Before adding a prioritised care programme to the digitalisation roadmap mentioned above I will commission a risk analysis, which will also consider funding issues.

5 Closing remarks

This letter outlines how I intend to take more control and introduce a statutory obligation to improve electronic data exchange in healthcare. I aim to submit a proposal on this statutory obligation to the House in 2019. The proposal is currently being drafted, which will take some time because the statutory obligation for electronic data exchange will have to apply to all sectors of healthcare, and will be binding on care professionals, care institutions, infrastructures for electronic data exchange and IT suppliers.

I wrote in an earlier letter to the House that more and better electronic data exchange could potentially reduce the administrative burden.[15] I do of course aim to avoid any unnecessary increase in care institutions' administrative burden and in healthcare costs. I will also ascertain whether the various measures lead to any overlap or duplication. I will therefore begin with a risk analysis of the actions and measures mentioned, and as requested in the motion submitted to the House by Raemakers *et al.*,[16] I will report on this analysis in a letter to be sent to parliament before 1 April 2019. The letter will also specify the actual data exchange processes to be digitalised by parties in the healthcare sector over the next few years in a managed, step-by-step approach. In order to ensure progress is sufficiently fast, I will draw up a programme and a plan which I will send to the House before summer 2019, incorporating the actions set out in this letter.

[14] https://www.tweedekamer.nl/kamerstukken/detail?id=2018Z18441&did=2018D49371.
[15] Parliamentary Papers 25 424, no. 388.
[16] House of Representatives, session 2017-2018, 29515, n. 46.