Medical Informatics Europe '96
J. Brender et al. (Eds.)
IOS Press, 1996

IT to PATIENTS - What Else ?

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Abstract. For more than 30 years Kommunedata has developed information systems for handling patient-related data within the healthcare sector. Terms like "focus on the patient" were used, but the IT-solutions only cared about the healthcare professionals.

Now the time has come to change this, to actually include "human facets" into IT solutions by developing systems for the patients and used by the patients. In that way we can unleash the forces which rest within patient associations and the patients themselves, thus using the natural incentive for prevention and care.

We have developed systems for the healthcare sector in Denmark for 30 years - with a special emphasis on Hospital Information Systems. We said that we would - and maybe even tried to - "focus on the patient", but nevertheless development was aimed first at administrators and now at doctors and nurses

Now its time to develop IT for the patients themselves!

1. Motto: IT used by the patient for the patient

Following the publication of the Danish government report, "Info-Society 2000" [1], the next step is to start making strategies for the development of IT solutions which can by used by the patients and which directly benefit the patients.

After the Computer-based Patient Record (CPR) IT to patients will become the next great challenge which faces IT professionals in co-operation with citizens, patients, patient associations and healthcare professionals.

This gives the concept "Human facet" a double meaning. For one thing, the use of IT will have a direct positive effect on the health and quality of life of the individual, and for another, it will put high demands on the design and ethics of the IT-solution to ensure its suitability for "Homo Sapiens".

On the other hand, it is difficult to imagine anyone more interested in improving his health than the patient himself. We are therefore faced with the challenge of releasing the energy of the patients through the design of the IT solution - which brings the vast know-how which resides within patient associations very much into the picture.

Goals

- *By 1998 tests with IT for the patient in co-operation with a patient association must be implemented.*
- *By 2000 we need to formulate a national strategy for the development of general IT services in the healthcare sector for patients and citizens.*
- *By 2002 these services must be available for anyone who may wish to use them.*

This goal is far from being ambitious and is very realistic indeed.

We could say for that matter that the initiative should have been included in the Danish Dybkjær-Christensen report titled "Info-Society 2000", as this report points to the wide, democratic use of IT. Across all chapters in the report it says: IT for All.

But in the chapter "Improved Healthcare with Faster Treatments" the emphasis is still on improving the system for the healthcare professionals - which is very reasonable per se. But initiatives which will put IT into the hands of the patients themselves are lacking!

Add to that that WHO may well still have a strategy on "Health For All by 2000" and the goal is clear. This strategy emphasises peoples' own responsibility of maintaining a healthy life through their way of life, prevention and taking an active part in avoiding and curing diseases. But where is that strategy today?

The "Health City" projects are still running, but do they extend the use IT to the man in the street?

2. The Situation Today

It is no exaggeration to say that no systems in the healthcare sector today have been developed with a view to providing an IT solution to the patient himself.

On the contrary, there are several systems which produce information, and in some cases even guidance, to the patient as a by-product.

The use of the Internet and the launching of the Danish company, Diatel, open a world of opportunities to bring information to the individual citizen or patient.

There is a well-defined infrastructure and a growing general knowledge of IT in Denmark.

The most decisive factor may well prove to be the development and application of the Computer-based Patient Record which is based on the workplace of the doctors and nurses - and that's real close to the patient!

Add to that the expansion of communication solutions - especially through the Danish MedCom project - and you have the foundation for developing solutions for the patients.

But it is just as important to understand that just as CPR is no further development of administrative systems, IT solutions to the patient are not a further development of CPR. We have to start at the citizen or the patient himself and then take it from there to see what benefits the individual in the situation in question.

3. How Did We Get This Far?

30 years of development of systems for the healthcare sector in Denmark can be summarised as follows:

1st generation which was merely administrative batch systems whose main object was an overall statement of the production within admitted patients.

In Denmark names like "The Blue System" and "M-70" are household names in that connection. There was not much "human facet" in that solution, neither in the user interface nor in the help it provided for the actual patients.

The 2nd generation HIS's were on-line systems with administrative as well as certain medical information. However, the systems were usually used by administrative personnel and medical secretaries. Names like "The Red System" and for example the "Patient Administrative System" of the County of Funen belong to this category.

The well-developed Danish health insurance system deserves mentioning in this context.

We are getting a little closer to the patient, but not much.

3rd generation systems become large integrated systems which collect large volumes of data about patients, and gradually more personnel categories, such as doctors, nurses, orderlies - not to mention administrative personnel and medical secretaries - start using the system.

The systems send letters, etc. to the patients, for example with instructions of preparations for X-ray examination or an admission to the hospital.

Names like "The Green System" and the HIS of the county of Northern Jutland belong in this category - and like certain laboratory systems start to communicate with general practitioners and generate printouts which can be handed out with kind guidance to the patients.

At the same time a vast improvement of patient record system for GP practices takes place, so we are getting close to the patient, but still, the main purpose is IT for the healthcare professional.

And now we get to the patient record which gets close to the workplace of the individual doctor or nurse. The system focuses on the patient to the extent that the information is all about the patient and in some cases even written together with the patient.

At the same time we have started the "information and communication revolution" which gives computer power to the people. The Internet, Diatel, teaching in schools, off-the-shelf packages at prices which anyone can afford if they set their will at it - that's where we are now!

4. Different Opportunities

The principle of IT solutions is not what they are in their own right - even though there is a tremendous focus on the technology itself today - but what they can offer the user.

Will the doctor become a better doctor - will the nurse become a better nurse, professionally speaking? Does the use of IT support the existing know-how and is it possible to refine it through the use of IT? Well, that's the big question!

In the same way you could ask yourself: Will the patient become a "better patient"? Do we exploit the know-how of the patient or her relatives or the patient associations which especially have a thorough knowledge of chronic diseases?

The IT solution which can unleash that power and exploit the know-how together with the healthcare professionals is worth millions - well, more than that, for surely the quality of life cannot be measured in terms of money?

Let's start at the hospital and thus give the patient more information and make "self-service" available, for example:

- Setting up "preventive machines" in the lobby and in waiting rooms.
- Teletext in wards with information about the patient's disease, post-treatment and other conditions after the discharge.
- Information about special diet.

We may also start in the very well-organised patient associations and give them the opportunity to give aid, guidance and information through the use of IT, for example:

- Establishing networks and enquiry opportunities for members.
- Information about new treatments.
- Information about new equipment.

Finally, we may take our starting point at the actual patient

- Information through Diatel to manuals of medicine.
- Information from and questions to patient association or general practitioner.
- Information about hospitals for choice of hospital which may be handled together with the general practitioner.
- Interactive medical guide for preliminary examinations and prevention.

The possibilities are infinite - it's a question of starting where the usefulness is greatest - and who would be a better judge of that than the actual patients - possibly in collaboration with patient associations and general practitioners.

5. Recommendation

In Denmark there is a firmly established infrastructure for the use of IT within healthcare.

The communication network is well developed and soon 3/4 of all Danish homes will have a PC.

HIS systems are well developed and through the MedCom project communication within healthcare has been given a great impetus. This trend will prevail and the result will be ordinary stable communication solutions.

The next trend - The Computer-based Patient Record - has taken its first tentative, but confident steps, and will no doubt consolidate itself within healthcare if it keeps on showing results.

As the purpose of all these systems is to help the patients it seems obvious to develop IT-solutions for the actual patients. In that way we can unleash the forces which rest within patient associations and the patients themselves, thus using the natural incentive for prevention and cure.

This can be done through pilot projects with participation of patients, patient associations and healthcare professionals.

Such pilot projects must be launched by 1998.

References

[1] Info-Society 2000, Ministry of Research, Denmark, November 1995.