

Talk to me, but rather: talk to each other

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During a yearly routine check-up for my alopecia in a hospital on the other side of the country, a small cancerous mass was discovered on my scalp. The dermatologist assured me it was not an immediate concern, but that it should be removed for investigation within a couple weeks nonetheless, along with an assessment of all the freckles and moles on my body.

Since there was no rush, I asked her if it could be removed at my local clinic. This was no problem. She would send a referral to my general practitioner that same day. Within 2 weeks, I would be called to schedule an appointment.

Three weeks later, I was still waiting for that call. Although I was not particularly concerned about the mass, it was always in the back of my head since it was discovered. An afterthought ever-so-slowly growing, like the mass itself. My husband was quite concerned from the get-go though, and he urged me to inquire with my practitioner's office about the referral. The doctor's assistant on the other side of the line was clearly not amused. 'We received nothing, but why do we have to be involved? Do they even have an inkling how swamped we are? The dermatologist should just send this referral to the local clinic, not to us. You can go and call them to tell them that.'

Being brushed off with very present annoyance, with a newly acquired assignment to boot, didn't feel great. But being understanding of the doctor's assistant's plight, I called the hospital. They informed me the dermatologist forgot to send it, but it wouldn't be an issue to send it to my local clinic instead of my general practitioner. I was assured my local clinic would call me to schedule an appointment for removal of the mass in, again, 2 weeks time. I wasn't feeling that assured anymore.

3 weeks later. Still no call. I checked my digital patient file with the hospital, which showed the referral was sent by email. Nothing in my digital patient environment with my local clinic though, which granted, was a slightly different system—but practically a twin of the other hospital's system. When I checked, I was informed that my local clinic does not communicate patient information electronically. What? But both hospitals use their very similar systems for encrypted patient files to communicate with me. So why can't a simple message be exchanged between two hospitals? Nothing or no one ever implied before that hospitals do not communicate digitally with each other. It felt like a weird time to casually find that out.

I decided to call the dermatology department of my local clinic. The lady on the other end of the line did not have an answer to my questions, but a question right back at me: if I could call and

ask the hospital to send them the referral I needed by fax.

By now, I was more perturbed with the ease with which both hospitals were leaning on my efforts to exchange a simple doctor's referral, rather than they were on responding to my carcinoma. Is it so hard for dermatology departments to arrange this without my involvement? Is it not their responsibility to make sure I get the care I need?

I called the hospital conveying the local clinic's message, to which the operator chuckled.

'A fax, really? Well, we only communicate electronically. Please hold, I'll see what we can do.'

What they could do, was send the referral to my personal email address as they did not know who to send it to (as if I did know), so I could forward it to my local clinic. Having lost all confidence in both hospital's communication chops, I called my local clinic first to ask which email this should be forwarded to.

'No, you can't send us patient information as a patient. Please print it and send it by post... or bring the print to our dermatology department's desk. That's the best we can do. Sorry.'

In short and in the end, I was responsible for getting my own doctor's referral from the hospital to my local clinic. This experience has taught me that I can't rely on 'interhospital' communication. A shining example of what could be achieved in terms of efficiency, patient experience and the work of being a patient, if digital patient files and communication were better used between hospitals.

Now I work in communication, know my way around encrypted online environments and can afford some patience. But I can only imagine what someone less tech—or communication-savvy might feel in terms of frustration, helplessness and loss of confidence and trust in their medical professionals. Especially when in need of more urgent care—either from a medical or personal point of view. I only got a taste of it. And it made me feel like an insignificant number in the healthcare bureaucracy and industry, instead of a person.

In my view there are at least two responsive solutions to this messy situation. First, if healthcare facilities have not collaboratively chosen a single approach to communicate to each other, or more specifically, to share referrals, why isn't there a place to find what the possible ways of communicating are between different (digital) patient environments? It seems to me that knowing how to contact colleagues in different healthcare facilities is part of training on the job—and it prevents patients from taking on this



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part-time job next to their daily life responsibilities. Second, what a difference it would have made if one of the hospital staff members I contacted had said to me: 'I understand this doesn't feel right, this shouldn't be your problem.' This solution takes no time at all, can be implemented as we speak, and I wouldn't have felt like a nuisance while I tried to work my way through the system.

The way I see it, healthcare should start with clear communication to reassure a patient in uncertain times, and to minimise time needlessly lost or spent. Some patient work is of course to be expected. But it was an unpleasant surprise to find this diverting of responsibility, instead of communication and

cooperation between hospitals. The means are there, so what is holding the solution back?

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