Self-Monitoring

The missing dimension of Cancer Survivorship

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survivors will live many years with it

So it may be of interest to know if you are getting better or worse

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Alas, the doctors will only be able to tell you when it is changed big time

"The lumps are bigger"

"The shadows are smaller"

Than 3/6/12 months ago

What they cannot tell you is whether you are getting better or worse week by week; in practice, often hardly month by month

Now, you know that something's are supposed to help, and something's harm:

exercise, no smoking, no alcohol, no obesity, and many things touted on the web

But: are they actually working in your case?

You want/need to know at least weekly, if not daily – in between doctor visits

What to do?

You can do molecular cancer markers, not much favoured by most of the doctors I've had.

These require a sample to be sent away, with results a week or so later.

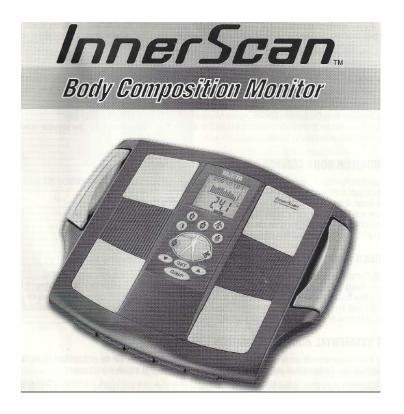
Useful, but still a time delay

Of course, what you'd really like, is a more or less continuous – perhaps daily (a hypochondriacs dream) – indication of whether you are getting better or not.

When I was diagnosed with terminal cancer and told there was nothing they could do for me; go home and make final preparations; I did what any self-respecting QSer would do:

I started measuring even more of my lifestyle in the hope of surviving longer.

Amongst the many things I did, was buy a body composition monitor



Another thing I did, against the advice of the doctors ("waste of time; they only tell you you've got cancer — and we know you do have"), was to do molecular cancer markers — just occasionally at first, now monthly. This became a measure of my cancerousness; because they do actually come with a continuous scale.

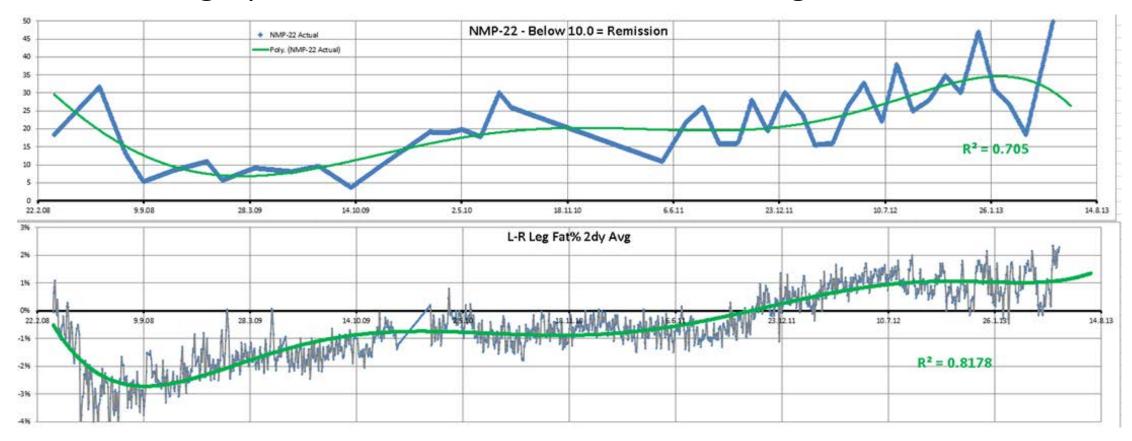
With this, I can measure a whole range of body composition things – weight, fat, muscle-mass, water, and – most importantly – of each limb.

From the latter, I could calculate the differences.

Why would I do this? Initially, for no other reason than I am a nerd/geek – I like playing with numbers.

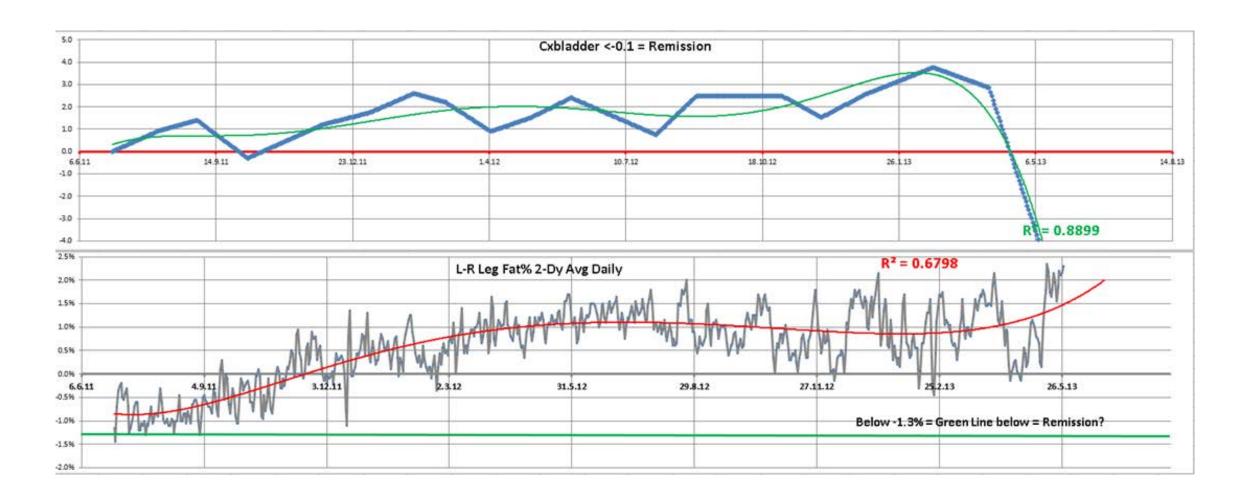
In the fullness of time, with my constant looking at all these numbers graphically, I noticed that the – I have to be careful here – the difference of the fat of each leg (OK, I nearly said something like: "the fat between the legs"; oops, there, I did it) seemed to roughly parallel the changes in cancerousness

And so to the results First, the graphs of the cancerousness and the leg out-of-balanceness



Note: Initial diagnosis Oct '07; chemo Feb-Jul '08; some cancer June '11; worse Jan '13; chemo Mar-Apr '13

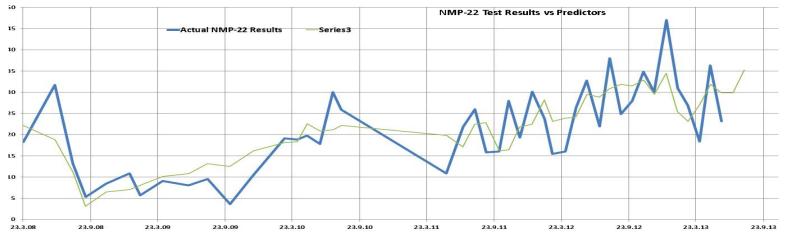
And the second one, specific to my cancer: Cxbladder (the other two are more general)



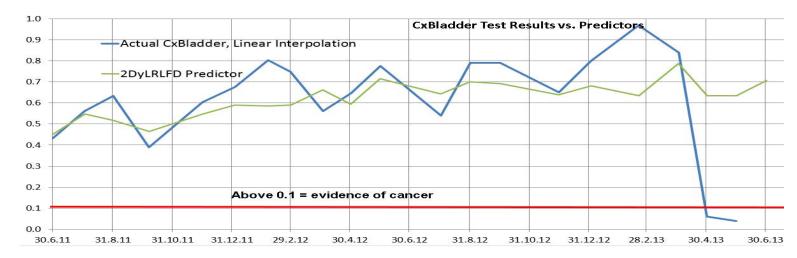
Next, the stats: the correlation between the molecular cancer markers and my cancer markers – of which I found 4: two body composition ones and two urine ones

	27.5.13	LRLFD	CORRELATIO My Markers		<u>NS</u>		
			LRLFD	ORP	rH2	Combined	
		7DyAvg	2DyAvg	Dev		All 4	n
	NMP-22	0.7816	0.8083	0.6881	-0.3600	0.8017	43
Molecul	Cxbladder	0.4011	0.5077	0.6524	-0.0676	0.6361	19
Markers	CEA	-0.5382	-0.5074	-0.9401	0.9189	0.9518	10
	CA19-9	-0.6245	-0.6305	-0.6770	0.5953	0.7327	10
	Abs Averag	0.5864	0.6135	0.7394	0.4854	0.7806	

Plot of Molecular Cancer Marker NMP-22 vs. 2 Day Avg. L-R Leg Fat Difference -74 Days



Plot of Molecular Cancer Marker Cxbladder vs. 2 Day Avg. L-R Leg Fat Difference



The take-home message from the previous table is that there are easy surrogates to the molecular biomarkers, that are both available to the patient and could be done daily, and can be done inbetween times for self-assessment

That of the fat difference of the legs is the one I think is credible, easy, repeatable, and a continuous metric usable for data analysis. However, neither my biomarkers nor the molecular ones are a substitute for the traditional assessments that the medical professionals do.

Please note:

This is not a substitute for the consulting with medical experts – it is something to use inbetween visits to them

My theory is not yet proven – tho' there's a lot of supportive research (see my blog - www.bladdercancerfight.blogspot.co.uk)

This out-of-balanceness may turn out to be a general health measure – something like a thermometer, and so have wider application

Finally

Self-monitoring with a body composition monitor is a useful tool for assessing cancer progress between doctor visits, potentially allowing lifestyle relationships with it to be explored.