Elective at the Immunology, Haematology and Rheumatology Unit of the Necker Institute: a few thoughts on my learning objectives

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What are the specialist local conditions, particularly genetic, that occur in France and require specialist tertiary care, and are there any differences between the French population and our English population

I'm curious about consanguinity – why is it still a thing? And is it more of a thing in France than in the UK? I'm not sure what proportion of our patients are the progeny of consanguine relationships, but when it comes to producing patients with profound illnesses, it seems that consanguinity is a significant risk factor. A brief search of the literature suggests that the French are slightly more keen on their cousins (0.7 – 1.2% incidence of consanguinity) than the British (0.04 – 0.4%) are on theirs[1]. It should be noted that the studies providing this data are not contemporaneous; the French high figure of 1.2% was from 1954, whereas the British low figure of 0.04% was from 2014. This discrepancy prevents any enlightening conclusions from being drawn.

There may be a strong influence of immigrant populations as well – there is a large North African immigrant community in France, some research suggests that consanguinity rate ranges from 40 to 49% of all marriages in Tunisia and from 29 to 33% in Morocco[2]. In the UK, personal experience with patients from the Sylethi/Bengali community of East London suggests some immigrant demographics are equally tight-knit. One recent study estimated the prevalence of consanguinity in the Bengali community of East London at 33%[3].

As genetic diseases are almost all individually quite rare (though collectively the focus more and more of chronic paediatric disease management) there is a fraternity of specialists which cross national boundaries and share expertise - when a patient's illness defies accurate characterisation in one location, it is possible that they be referred trans-nationally for assessment at another specialist centre, a sort of quaternary care. I met a series of patients from one Middle Eastern family that had been referred many years ago to the Necker from British colleagues for better elaboration of the disease aetiology. Since then, the family have been followed up at the Necker even though they've no other reason to visit France (tourism aside).

Aside from genetics, gastronomic differences can account for different disease burdens: I was lucky enough to attend a brief talk on the molecular mechanisms by which *Listeria monocytogenes* manages to propagate preferentially in the immunosuppressed. The speaker elegantly described the elegant studies which detailed bacterial ingress through goblet cells! They also stated that the

[1] http://www.consang.net/images/6/6a/Europe.pdf

[2] Anwar WA et al; Consanguinity and genetic diseases in North Africa and immigrants to Europe, *Eur J Public Health*; 2014; 24(Suppl 1); 57-63

[3] Bajaj Y et al; Causes of deafness in British Bangladeshi children: a prevalence twice that of the UK population cannot be accounted for by consanguinity alone; *Clin Otolaryngol*; 2009 Apr;34(2):113-9

French national reference centre had the greatest registry of pathological samples of Listeria due to (inter alia) a very French 'soft spot' for raw cheese.

How are referrals and shared care for complex chronic diseases are managed between two leading health systems

Payments – although France has a complex social insurance scheme which covers most health care services, the French patients at the Necker suffering from both chronic and serious conditions have their costs entirely paid for by the state. This does not apply to foreign patients, some of which are seen as essentially private patients, whereas others may have their costs met by their governments.

Shared care – a patient of 3 months too underweight for their BMT was considered for repatriation to their local hospital (Chartes) for ~ 6 weeks to optimize their health in the run-up to the treatment. There were a number of reasons for this, including that it would make family visits much easier as well as freeing up space on the ward. Chartres' capacity to provide adequate care was subjectively assessed by the tam ("c'est pas *top*, mais bon…": translation – "it's not great, but well…") and, in light of this rather lukewarm endorsement, a comprehensive list of required regular observations and investigations was drawn up to provide to Chartres'. Some felt this list was rather excessive, yet perhaps was is in order to ensure that they (at Chartes) appreciate the complexity and sensitivity of the patient.

I'd like to gain an appreciation of how pharmaceutical prescriptions are determined in France. Personally, I've experienced and witnessed a profoundly different attitude in sheer volume of prescriptions for relatively benign complaints, with French clinicians much keener on prescribing more drugs. I'd like to learn whyIs there a NICE equivalent?

In vain I searched for a suitable paper surveying prescription practices internationally, but I did then stumble upon a wonderful article in the Guardian on the subject of French overprescription with strong views expressed by a Professor Philippe Even, then director of the Necker Institut[4]! It included the startling statistic that the annual cost of medications per French citizen is 58% more than that of their British cousins (with equal life expectancy). Professor Even and his co-author Docteur Bernard Debre (also a French MP) had been tasked to assess national pharmaceutical prescriptions by then-President Sarkozy in light of deaths due to inappropriate use of the metabolic drug 'Mediator'. I'm curious to read the book as it apparently alleges that statins are completely useless, a finding at odds with numerous large, well-organized trials (eg 4S, AFCAPS, ASCOT, CARDS and JUPITER).

I'm already fluent in normal French but have little exposure to clinical French and hope to improve that dramatically

My tutor at Barts – the wondeful GP Dr Dev Ghadvi – advised his students that we had better make sure we spoke the language before we went anywhere on elective: if not we'd get almost nothing out of it, and would probably become something of a burden on the local resources as we'd need them to translate everything. I thought my French was good enough to allow me to understand what

[4] Kim Willsher, *Half of drugs prescribed in France useless or dangerous, say two specilists*, Guardian Newspaper, 14/09/2012

was going on, but I was wary of the fact that my medical French was pretty much nonexistent. However, as English has essentially become the *lingua franca* of science, and, to a lesser extent, other technical fields such as medicine, I hoped there would be enough similitude of terminology that I'd manage.

On this point, my experience has been quite varied: in clinical consultations, I've had no trouble as the technical vocabulary is simplified for the sake of the kids and the parents.

However, for the first few days on the wards, at staff meetings and during handover or case conferences the speed and complexity of the language has forced me to concentrate with such effort on the nature of what was being said that the clinical narrative often escaped me.

Futhermore, there's a willingness to use the brand name of drugs which I'd otherwise know the active ingredient (examples) which has required further study to appreciate. Also, sometimes the acronyms used were translated (IRM for MRI), sometimes not (PCA for patient-controlled analgesia was still PCA - when in French it would be probably be analgesie controlle par le patient, or ACP… which is doubly confusing as it's often prescribed for neonates and made me wonder whether we in England also call it PCA when it probably ought be PRN analgesia, or perhaps heuristic analgesia.

Also, the use of the term 'KT' for catheter proved confusing – was this a special catheter, an acronym, or something else? According to my colleagues, it was something of an abbreviation. It recalled to me the coffee mug favoured by my fully-French older brother which read: L.H.O.O.Q. I leave it to the reader to elucidate this witticism. This linguistic learning curve was steep but I now feel that I've climbed it sufficiently well to follow the narrative quite well. I do still dread being asked for my input.

When med school began, we were told that our vocabularies would double before it ended. It has not quite required tripling in order to get by in France, but there has been quite a lot gained.

Word Count (excluding title and headings): 1236